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The American University in Cairo
School of Humanities and Social Sciences

Cantus Lamentus:

Navigating HIV Positive Mothers Subjectivities in Egypt Post 2011

A Thesis Submitted to
The Department of Sociology, Anthropology, Psychology, and
Egyptology

In partial fulfillment of the requirements for the degree of
Master of Arts/Science

By Wesam Hassan

Under the supervision of

Dr. Hanan Sabea

Fall 2015

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Abstract

This thesis explores the subjectivities of mothers living with HIV in relation to the exercised techniques of governing HIV and AIDS in Egypt. Drawing on the experiences of women living with HIV, in addition to the analysis of the National HIV Strategic frameworks and national media press articles, this thesis traces major events related to the bio-politics of HIV in Egypt post-2011.

I conducted research with mothers living with HIV to explore how they perceived their individual experiences of living with HIV within the social and political context of Egypt post-2011. The research is an attempt to unravel glimpses of the events that affected their lives in the period from 2011 until 2015 as well as to understand how they assemble the trajectories of those events and mediate their social lives.

In this thesis I deploy the issue of HIV and AIDS as a prism to analyze and trace how biopower produces HIV positive subjectivities. It aspires to document as well as examine how HIV and AIDS are deployed in the social and political arena, especially since 2011. It navigates the stories of the main research interlocutors to understand how they perceive as well as negotiate the multiple faces of authorities in their lives to construct their own realities.

My aim is also to understand how HIV positive subjectivities are shaped and continuously shaping the dominant discourse on HIV and the political. The discourse here is conceptualized as a totality of circulated manifestations of the thinking, speaking, acting and the knowledge of the subjects that is continuously in an unfolding process (Foucault, 1972). Hence, HIV and AIDS related events and rhetoric are orbiting within interlinked discourses of power and authorities such as the medical, the social, the religious, the economic and the political.

Chapter One: Introduction

Overview

In January 2011, Egyptians witnessed flares of a revolution being lit up in Tahrir Square. However, very few Egyptians knew that the draft of the HIV National AIDS Strategy in Egypt for 2012-2016 was drafted during the same month. The strategy was being written after a series of meetings between governmental, non-governmental entities and people living with HIV, and guided by larger global governance frameworks that Egypt should follow in relation to HIV and AIDS.

This thesis explores the subjectivities of mothers living with HIV in relation to the exercised techniques of governing HIV and AIDS in Egypt. Drawing on the experiences of women living with HIV, in addition to the analysis of the National HIV Strategic frameworks and national media press articles, this thesis traces major events related to the bio-politics of HIV in Egypt post-2011.

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I opt to use the political here instead of the public, because “there is no face in which the political doesn’t appear. Power is everywhere” (Navaro-Yashin, 2002, p. 3). The political here is conceptualized, as argued by Yael Navaro Yashin in her book *Faces of the state: secularism and public life in Turkey* (2002) as not confined to the boundaries “of its rationalized institutional and discursive forms, the political here is unsiteable” (Navaro-Yashin, 2002, p. 2). The question of the political in this document is linked but not limited to power and its circulation. Here, I intend to add to the “political” the different forms of resisting, escaping and/or negotiating different power representations, whether as a personal everyday mundane act or a collective one. Hence, what constitutes the political in this document is the mutable field resulting from the two forces (the one of authoritative and the other of resisting nature) coming in a subtle and or direct confrontation together as if in a fire dance ritual. The process of governmentality, as described by Foucault, deployed knowledge as power in rationalized and bureaucratic entities to discipline people (Foucault M. , 1991). Foucault’s concept of discipline was later theorized by Deleuze who argued that power is diffuse and dispersed in “our society of control” (Deleuze, 1992) in which we can say that power has no-site as adopted by Yael Navaro-Yashin (2002). Subjects, who negotiate possibilities of altering realities within dominant control and discipline, are considered political as stated by Badiou (2008) and reflected in details under Subjectivity in literature review section.

In the context of the thesis, contracting HIV and living with it, can provide a symbolic picture, allowing us to examine the analogy between a physical state and a political state in which the body is positioned as a “site of action” (Biehl, 2007). It symbolizes “the interconnectedness of human and national entities” (Biehl, 2007, p. 8) rather than looking at them as a binary between a human and an institutional entity. In other words, the mother once infected with HIV is continuously reminded of a fragile immune system that she tries to control or manage, while going through phases of relapse and recovery. She does that within complex social, political and economic systems in which power is reproduced and circulated in a rhizomic way.

The moment of rupture caused by knowing the positive HIV status creates a state of psychological, emotional as well as social disturbance, in which she perceives it as passing through to the “unknown” and its related panics. At this point, configuring new realities is somehow distant because of the momentary recognition of

the precarious nature of life and experiencing it, which turns her future as she used to imagine it into a past. Here, the juncture happen between holding on to old techniques to assemble her life or configure new ones, would create either rigid or flexible state. To attain a state of plasticity to move on in life, time passing after the moment of diagnosis can be one of the factors needed among others. However, techniques exercised by her to access the process of plasticity vary and are not done once and for all, it is a continuous process. Institutional entities, face transformation to the “unknown” panics in times, for example, of toppling old well known regimes. Maintaining those entities intact in times of transformation, gives rise to old banal or new techniques of navigating life. How those entities would be able to embrace the changing nature of things leading to which direction is a question worth tracing. The analogy here is meant to situate concepts of agency and structure within larger complicated networks of systems and events, rather than looking at them as either dual or binary.

The main research question is how bio-power produces political subjectivities, which methodologically I approach by focusing on HIV positive mothers. Specifically, I explore how bio-power techniques are exercised in regards to the issue of HIV and AIDS in Egypt to produce HIV positive subjectivities, focusing on the last five years from 2011- 2015. Furthermore, what are the techniques used in governing AIDS in Egypt and who exercises them? How do the mothers living with HIV perceive and negotiate the medical discourse of testing, care and treatment? Considering that living with HIV disturbs social life, how do they mediate and reflect on the living with HIV and AIDS in their everyday lives?

Thesis problematic and significance

I choose HIV and AIDS to understand bio-power techniques and its bio-politics instead of other topics like Hepatitis C or birth control mainly because HIV and AIDS has been for a long time used in creating public panic. This panic is driven by morality, fear or ignorance politics and apparatuses and has been related to the nature of HIV and AIDS as one of the relatively new medical pathologies that has no cure yet.

Not only do HIV and AIDS have no cure yet, but also and despite the work of various global development and research entities along with community organizations

to talk about how it is being transmitted, its stigma is still prevalent. HIV transmission is linked to sexual acts and injecting illegal drugs. At the beginning, it was associated with homosexual sexual acts, which further contributed to the stigma around it (Farmer, 1992). Cancer can be fatal; however, it is not stigmatized the way HIV is, due to its unknown occurrence and reason thereof. Medical doctors can advise on what to do to avoid getting cancer; however, it does not prevent it from happening. This is further complicated by the prevalence of the conviction in Egypt that disease is a test from God and that bodies belong to God (Hamdy, 2012).

HIV rhetoric and attitudes towards it are not the same like cancer because of the HIV linkage to unacceptable acts that are criminalized by the law or disgraced by the public. Global, national and community entities working on HIV and AIDS emphasize that disseminating accurate information about HIV and AIDS and how to prevent it would change the attitude towards AIDS. However, I argue that the morality apparatus is much more influential than correct scientific knowledge in Egypt. The deconstruction of the imaginary moral code, which is internalized and circulated within the subjects of the society, remains distant from HIV discourse even within people who are living with HIV. Hence, internalized stigma of living with HIV dominates their lived experiences. Emphasizing only the dissemination of “correct scientific information” on HIV without regard to the meanings and politics morality and how authorities deploy the morality apparatus, rather than diminish, in fact expands the stigma related to HIV and its consequences.

In Egypt post 2011, the visible deployment of morality as an apparatus, which would preserve the country and bring it to “the shore of safety and stability” was manifested in the events referred to in the National AIDS Strategy in Egypt document. As I demonstrate, the public attention was deflected through the practices of security and media entities using morality and nationalism as tools to disperse their powers. The announcing a device to cure HIV and AIDS by the Armed Forces in February 2014 as well as the rising and multiple arrests of gay people and scandalizing them are main instances of this tactics. I argue that creating moral

panics, as a technique deployed by the state, further influences the HIV discourse and its related stigma¹.

This thesis methodologically traces the narratives and practices enacted by the main research interlocutors, national media and official national documents in an attempt to analyze the techniques of bio-power exercised and therefore, shape HIV positive mothers' subjectivities. My position in this research as a principle investigator is informed by my past experience as a professional working in the area of sexual and reproductive health and rights, a physician by training, and a mother. Hence, intersubjectivity is a key concept in the theoretical background and fieldwork of this research.

Different governmental and non-governmental entities are part and parcel of the care and treatment system that influences the lives of people living with HIV in Egypt. People living with HIV continuously encounter those entities, considering the nature of HIV as a chronic medical disease; to give only one example of such continuous encounters is the fact that treatment can only be dispersed from the Ministry of Health and its outlets. My interlocutors' reflections on the public and personal encounters with different entities are at the core of the thesis.

A published report of a qualitative study titled "The Agony of AIDS: A Qualitative Study on the Experience of AIDS in Egypt" was conducted by the Egyptian Society for Population Studies and Reproductive Health (ESPSRH). Produced in May 2010, with support from the Ford Foundation, the study built on an assessment of HIV and AIDS situation and its socio-cultural, political, demographic and economic impacts conducted in 2008 by ESPSRH with the support of an interdisciplinary research group in areas of medical anthropology, HIV/AIDS, psychiatric counseling, health economics, and demography (Khatab, 2010). Descriptive, qualitative and quantitative methods in gathering data were used, such as in-depth structured interviews with 250 people living with HIV (78 women, 172 men) and their families, questionnaires, focus groups with the general public on HIV and its related stigma (Khatab, 2010).

¹ The state is represented in many faces and not confined to institutions or entities, as represented in faces of media, police, authority figures in public life such as religion, armed forces, medicine and family (Navaro-Yashin, 2002).

The sample was selected in collaboration with National AIDS Program from a little over 1000 individuals living with HIV and AIDS and regularly followed up by the staff of the National AIDS Program (Khattab, 2010). The study described the socio-cultural and decision-making environments and their impact on living with HIV as well as giving an analysis of the economic impact of HIV in Egypt and offering recommendations to policy makers. It addressed, also, factors affecting taking HIV medications and adherence to it. The political domain was discussed as the national response of HIV confined to the National AIDS program under the Ministry of Health and the environment of health service provisions. The report contains statistics as well as descriptive responses related to HIV and AIDS knowledge, stigma within society and services and treatment available.

The study acknowledges that the sample is not representative of the Egyptian society but it acts as a “pointer” to the bigger picture of HIV in Egypt (Khattab, 2010). The study recognizes also that people living with HIV are negatively treated and commonly avoided by health service providers especially nurses even in specialized fever hospitals (*homiya*t hospitals), which are considered as the governmental places that provide care for AIDS and HIV related symptoms (Khattab, 2010). In October 2014, there was another published report by the same organization, ESPSRH, presenting case studies of 5 women and 5 men living with HIV (Khattab, 2014). The 45-page publication documented the in depth interviews with selected individuals, after completing a national stigma index study that started in 2012 and was concluded in June 2014 (Khattab, 2014). The case studies, as a qualitative descriptive approach, aimed at documenting the life histories of HIV diagnosis and family and partners attitudes towards the person living with HIV (Khattab, 2014).

My research in contrast is ethnographic, which builds on knowledge generated in those two reports, and engages the practices enacted and narratives articulated by the mothers in the Egyptian political and social environment post 2011. In other words, I locate my interlocutors within prevailing neoliberal realities that frame people within the network of antipodes of self-responsibility of survival, distraction, success, efficiency, destruction as well as production. The main quest is to reflect on

bio-politics techniques and have a closer look at it through the prism of HIV and AIDS.

Two of the research interlocutors had participated in the case studies conducted by ESPSRH describing the period of their early diagnosis and attitudes of their families and partners. The two have mentioned that they participated in a research with National AIDS Program when we first met. By the time I was doing the fieldwork, I had read the ESPSRH publication and was able to link the stories because the details of the how they knew about the diagnosis and their family and partner stories were shared with me. In addition to that, I was particularly interested in navigating how they articulated coping with certain personal events and trauma that affected their lives and how that was reflected in their narratives.

Methodology

I believe in the complexity of the human story, and that there is no way you can tell that story in one way and say, ‘this is it.’ Always there will be someone who can tell it differently depending on where they are standing ... this is the way I think the world’s stories should be told: from many different perspectives. (Chinua Achebe: *The Art of Fiction*,” interviewed by Jerome Brooks in *The Paris Review*, Issue #133, Winter 1994)

I draw on Joao Biehl’s notion of understanding subjectivities by understanding the making and the remaking of the body as a “site of action” in its political, social as well as somatic processes (Biehl, 2007). Additionally, I examine “how do modes of subjectivity intertwine with particular configurations of political, economic, and medical institutions? How, under quite new conditions, do people value life and relationships” (Biehl, 2007, p. 8). In other words, in this research I look closely at how women negotiate the dominant political, social as well as medical surroundings while performing their roles as mothers, workers, Egyptians, and women of particular class positions and cultural backgrounds. The narratives are infused throughout the thesis in conversation with theorists, scholars, documents, events and products of media outlets in an attempt to unravel the “living” techniques amidst the spider web of dominant discourses.

I use ethnography as the main research methodology that enables me to narrate the stories of the main research interlocutors and situate their narratives within

the larger context. I aim at illuminating their perspectives within the big picture in conversation with what is happening in their own political and social surroundings. Ethnographic research is dynamic and iterative process, which guarantees the visibility of the agency of the research interlocutors. Different data collection methods that are used in ethnography assist in dismantling the hierarchy of the way research is conducted. The merge between abstract social theories and field techniques provide an analytical perspective, giving the space to the readers to engage in their own conclusions and reflections.

The methods used to do the ethnography focus on interpersonal communication with the research interlocutors as well as a review of documents, national press media and social media outlets relevant to the topic of the research. The documents I focus on are the National HIV Strategic Plan for 2012-2016 and 2015-2020, HIV grant concept note for the Global Fund developed in June 2015, and the Global Fund Investigation report September 2015. Participant observation was deployed as a central part to the techniques of the research to pay full attention to how the narratives were told and in which context. Individual unstructured interviews were conducted with mothers living with HIV along with structured interviews with UN personnel, civil society workers, and psychologists working with people living with HIV.

The main aim of analyzing the written documents and national press media was to understand the reasons and process of developing the documents along with examining how HIV and AIDS related work is reflected upon and implemented. In addition to understanding the challenging situation of the health sector in Egypt, I examined a Facebook group called “Egyptian Health Sector Reform” that has more than 6,000 members from the medical field and interested activists holding different positions in the medical and civil society fields. The group members offered a lot of official documents related to national health system in addition to the group’s suggested strategies to improve the Egyptian Health sector. The suggested strategies by the group members are said to serve the interests of the patients, health sectors workers, and medical doctors in Egypt, a theme I highlight in Chapter Two.

My position, the interlocutors and venues of fieldwork

The processing of the details and the analysis of the written and uttered words were influenced by the use of social theories in addition to my background as an anthropologist, a medical doctor by training, and an activist in the area of personal rights including sexual and reproductive health and rights. To reflect on my position in this research, besides being the researcher, I have volunteered and worked on the issue of sexual and reproductive health and rights since 2002 at the beginning of my medical education. HIV and AIDS communities and strategic work were a central part of the topics that I focused on; including providing voluntary counseling to newly diagnosed people on where to start from to manage the disease. Hence, I am familiar with the health sector and development work environments; however, ethnography provided me with more understanding of the research interlocutors' own realities. Interacting with the mothers' stories and following the events they highlighted in the past five years, captured a different picture of the field and HIV and AIDS in Egypt. The narratives of the mothers about the events that affected their lives situated their stories within the larger political framework. Hence, this ethnographic work contributes to, as Joao Biehl stated when he wrote about ethnographic work examining subjectivities, "revealing human and institutional interconnectedness to generalize ethnographic findings". (Biehl, 2007, p. 8)

My focus on mothers who are raising their children and living their everyday with their precarious conditions and with a chronic illness that has its own social, personal, as well as medical heaviness, is motivated by my own personal quest to configure motherhood as a daily practice and as a concept. The mothers have been all living with HIV for more than 5 years. I intended to understand how they manage their lives and deal with the effects of the diagnosis on their social and medical lives. I wanted to understand how do they negotiate to maintain their social lives and to support their families while experiencing how to cope with the burden of HIV as a chronic disease. The selection of mothers, who have been diagnosed for more than five years, helped me to understand the negotiation process of the social that they underwent over a five-year span and the universe of meaning associated with it. In addition I examined their own narratives, which reflected their journey of seeking treatment and care for the past five years (2011-2015) in relation to the reactions of the larger context towards their diagnosis and the moral politics associated with it.

I conducted fieldwork in Greater Cairo in spring 2015 with 5 mothers living with HIV. They are in the mid- thirties and all of them come from working class and live in poor urban settings in Greater Cairo, in areas like Helwan, Marg, Khosos, Haram, and the outskirts of Maadi. Two of them are working on voluntary basis as social actors providing support to women who are newly diagnosed with HIV. They all experienced working before in various ad-hoc unstable jobs. One of them was working in a popular restaurant in Cairo and she left the job because rumors got to the management that she is HIV positive and they wanted to take her for HIV blood testing. The others were learning the craft of tailoring cloths by themselves and with some NGOs to be able to support their kids. Another one worked in a hair salon. None of them is working in a permanent fixed-term job and hence they have neither social nor health insurance. I contacted NGOs that work in the field of HIV and AIDS in Egypt to present the scope of the research and get their approval to do the fieldwork and meet with potential mothers. One of the NGOs approved and we agreed about the importance of keeping the identity of the mothers confidential and using pseudo names. Moreover, we agreed to conceal any detail that might give any hint throughout the research and in the final document about the address and or work of the research interlocutors. The NGO manager approved to share the announcement of the research with the mothers who visit the NGO for support services. At the end I was able to do the interviews with 5 mothers. Most of the interviews were conducted individually in a closed room at the NGO based on the request of the mothers because they would not feel safe talking in public venues for the long hours of our interviews. Some of the interviews were conducted in the house of one of the mothers.

The NGO management showed respect and did not interrupt our interviews. Later on, structured interviews were conducted with the NGO manager and the responsible people in charge of providing psychosocial support to people living with HIV. The name and address of the NGO in which the fieldwork announcement was done are concealed for protections. The main reason is highlighted in chapter two of the thesis, as we will read the incidence of investigating one of the NGOs working in HIV and AIDS prevention by Ministry of Social Solidarity in Egypt based on a complaint from an Egyptian citizen claiming that they are shaming the morality in thr Egyptian society by disseminating condoms and information about safe sex.

My previous work while I was working in UN programs and community services NGOs allowed me to get technical knowledge on how to provide support for people living with HIV, especially on the medical and psychosocial levels. There are multiple NGOs who form support groups, a term that is coined by community NGOs describing a technique to provide psychosocial support to people living with HIV, in Cairo and Alexandria only through weekly or bi-weekly meeting. People have to travel from other governorates to attend the group meetings and the National AIDS Program has to know the list and places that provide support group meetings. Other services provided by NGOs vary from working on micro-economic and vocational training for people living with HIV, to providing medical and legal support. Some NGOs do outreach work and counseling services for drug users as well as people living with HIV. For newly diagnosed people, the civil society is of help to provide guidance on where to go to get medication and understand the system of treatment and routine blood testing with the National AIDS program. All newly diagnosed cases referred to the National AIDS program have to be registered in its system to get the medication; otherwise, the services provided by the NGOs should be totally anonymous. Professionally, I used to focus on providing information to HIV positive people about how to know their legal, medical rights and from where to start the medical and psychosocial journey as well as how to deal with officials at the MOH in case of any misconduct. HIV positive people get free medication and do free routine laboratory testing in Ministry of Health, especially that laboratory testing for HIV and access to medications are expensive in private laboratories.

Building a rapport with the research interlocutors was facilitated first by the fact that I was aware of the journey that they go through for treatment and care, and second by the intersubjective dialogic relation that we had in our interviews. We unpacked our personal views and narratives as Egyptian women, mothers and people who are familiar with the system of HIV and AIDS care, treatment and testing. The interviews were not merely about collecting data, but about gaining knowledge on the basis of our shared experiences situated in the shared collective political and social surroundings. Most of the mothers preferred meeting outside of their neighborhood and their homes, mainly because, as one of them said when I asked her if we can meet at her house “I live in poor popular ‘*shabie*’ neighborhood and everyone would be curious to know who is the new face coming to visit me”.

While writing the final draft of the thesis, I still feel the intense emotions that we shared together during fieldwork. During our dialogues, we laughed, made jokes, and cried together on shared personal narratives. The shared public events that we all as Egyptians encountered such as the state violence during the start of the revolution in January 2011 and the announcement of a device developed by the Armed Forces that falsely claimed the complete cure HIV and AIDS and Hepatitis C, stirred shared bitterness and agony. Moreover, we bonded over our experience of pregnancy as well as specificities of the world of nurturing a child because I have a 5 years old son, who is the same age like some of their children. Their perceptions of motherhood daily practices amid the plight of living with HIV in Egypt were intriguing, particularly because of my previous understanding that caged the construct of motherhood within the walls of either the modern working mother who is supposed to excel in public and private spheres to be the figure of a “good mother”, or my previous readings that argued that the domestication of women was partially through the construct of motherhood. Hence, navigating their narratives displayed the intersection of the construct of motherhood along with class, and the universe of meaning of what does it mean to be a working class mother. On the other side, the dialogues in the structured interviews with community workers and UN personnel were facilitated by my previous professional experience and familiarity with the field of sexual and reproductive health and rights in Egypt.

Literature review

I use HIV and AIDS in this thesis as a prism to understand and disperse the exercised techniques of bio-power. The bio-power question is not limited to the state polices and governmental bodies, rather to the circulation of power through different hierarchies, entities and discourses. Boundaries between medical, social and political fields are imaginary and constructed. Hence, the HIV and AIDS topic is in and by itself a material disease, a reality as well as a metaphor. The metaphor used in this thesis not intended to romanticize the disease, yet it is used as a mirror representing the medicalization of social and legal issues as well as how a medical pathology is used to gain affluent popularity in the political realm. For instances, the case of the announced device by the Armed Forces that falsely claimed and promised a complete cure for HIV and the implementation of harm reduction as an approach as I will

describe later in the following chapters. HIV and AIDS are modern pathologies that are shaped by multiple forms and hierarchies of power, shaping the subjectivities of people affected by them. In these entangled realities, an unconscious internalization of the concept of “State” is not confined to governmental bodies, rather to the way authoritative actions and policing techniques internalized within as well as enacted by the people themselves, whether living with HIV or not.

HIV and AIDS thus act as an analytical lens for understanding the unquestioned foundational categories of the social order and of otherness. HIV and AIDS is one of multiple and intersected factors in a set of social, economic and political forces that render particular people more vulnerable than others. Their vulnerability comes from internalized social belief that there is a collective moral code and that by living with HIV, they have pushed the limit and even destroyed the social and moral code of the society in one way or another. Additionally, the ethos of the neoliberal world that we live have enforced self responsibility regarding living with the disease or protection against it within framework of economic inequality.

The literature review below guides the theoretical and conceptual framework of the thesis. It focuses on reviewing HIV and AIDS related scholarship, read through three main concepts of the thesis. Namely bio-politics, intersubjectivity and subjectivity.

Bio-politics

The ethico-political choice we have to make every day is to determine which is the main danger. (Michel Foucault, *On the Genealogy of Ethics: An overview of work in progress*, 1983, p. 256)

This quote can be analyzed to reflect on many situations and choices in our everyday life, whether we are consciously attentive to how we make those choices or not. Whether we ask ourselves about the driving forces that influence our decisions or we just respond spontaneously and unconsciously in a way that indicates the normalization of acts that are taken for granted just because they are part of the mainstream social discourse and regularized practices. However, I intend to relate this quote to the discourse of HIV and AIDS, in which the medical, social and political boundaries are elusive within a social field in which subjects are practicing their everyday. The field is conceptualized; according to the Pierre Bourdieu theorization

of the field, as a setting in which social positions are being shaped and reshaped in relation to the subjects' own surroundings (Hilgers, 2014). Subjects' agency, their social relations and capital, and everyday habitual practices are shaping and shaped by the specificities of their own settings and social fields. Power dynamics manifested in knowledge productions and class struggles produce hierarchical fields in which agency viz. a viz. structures are continuously changing and dynamic (Hilgers, 2014).

Living with HIV and AIDS is a continuous process of constructing and reconstructing new and old social fields. Family, friends and partners are at the forefront in the process of getting diagnosed with HIV for any person. This process of knowing the diagnosis turns into one of the main events of the life of the person living with HIV. Although I did not focus on the process of diagnosis as all my interlocutors were diagnosed more than 5 years ago, I find this period of anticipation and waiting for the test results from its onset as a crucial phase in life that would need timely examination while it is happening. Most of the social research on HIV and AIDS that I came across, deals with the process of diagnosis as a memory from the past, not a present agony manifested in anticipation and dealing with bureaucracy and uncertainties of different parties involved in the process of diagnosis. It is an intimate disease, in its modes of transmission as well as in all the discussions, thoughts and reflections that it affects and initiates. They search for new paths for socialization to develop social capital in which they share the status of HIV infection, and talk freely, like the cases in group meetings and outings for people living with HIV that is coined as "support groups". Additionally, the routine blood testing, getting monthly medications and various manifestation of any failure of the immune system to protect the body, increase the encounters with bureaucratic institutions that provide those services. On the social level, the link between contracting HIV and socially controversial acts such as drug use, homosexuality or sexual relationships contributes to the prior judgment and actions towards HIV and people living with it. Thus, the HIV and AIDS discourse provokes questions of what is legitimate and worth supporting with information and health care and what is illegitimate and does threaten the hegemonic moral code and is not worthy of political nor ethical support.

That would bring us to Foucault's quote above. The paradox expressed in the quote put the final decision on what we choose, between the hammer of politics and the anvil of ethics, drives us to ask what is identified as ethical and what is identified

as political. Determining the danger of HIV and AIDS has complicated bio-political dimensions that would affect the response towards the disease itself by different actors. What is more dangerous? Disseminating condoms as a preventive method that would protect the person from contracting HIV or the claimed arguments that making condoms available would lead to promiscuity and destructions of the moral code of the society? On the other hand, HIV positive people are being blamed because they do not share their status with medical doctors or with their partners. Moreover, what are the forces that shape the discourse of the response towards HIV and AIDS pandemic? And what lies beneath the surface of global unified action to combat the virus?

Bio-politics as a concept is intertwined with other concepts such as bio-power and governmentality that were presented in Foucault's work in 1970s. Foucault has defined bio-power as the social and political investments that are practiced and implemented through the circulation of power between different structures, to regulate the lives of the population. To put it in the words of Foucault, biopower is:

An explosion of numerous and diverse techniques for achieving the subjugations of bodies and the control of populations, bio-power brought life and its mechanism into the realm of explicit calculations and made knowledge-power an agent for the transformation of human life. (Foucault, 1976, p. 143).

Foucault dealt with analyzing and tracing the forms of power and authority practiced over human beings since the eighteenth century with the shift from treating the human being as a political and legal subject to be treated based on his biological and living being with focus on the natural functions and health of the individual and the population "the global mass" (Foucault, 2003). Human beings are treated as coded numbers with measures and percentages on large and collective scales such as population birth rate, mortality rate, HIV prevalence rate, and contraception and reproduction (Foucault, 2003).

The concept of governmentality was part and parcel of explaining the concept of bio-politics. The mechanisms of governing the other or one's self do find the base of bio-politics manifested in the relations either with others or with one's self with the main aim of controlling those social relations and providing a vision of how to keep records of nations' population (Foucault, 1991). Govern-mentality is a process, as

explained by Foucault; with means to an end (Foucault, 1991), the end would be the governing or controlling of transformations of people as collective or an individual. Means of governmentality can be deployed through security, education, medical and media apparatuses. The aim here is to understand the process and its means, rather than falling under the binary thinking of whether governmentality is negative or positive, whether it leads to predictability, idleness or productivity, or it leads to subjugation or bureaucratization. As Foucault described it:

governmentality is the process, or rather the result of the process, through which the state of justice of the Middle Ages, transformed into the administrative state during the fifteenth and sixteenth centuries, gradually becomes 'governmentalized'. (Foucault, 1991, p. 102)

Other scholars such as Nikolas Rose have built upon the work of Foucault to analyze the bio-political aspects of governing human beings through different policies especially those related to health. Rose has coined the concept of 'vital politics' in his book *The Politics of Life Itself: Biomedicine, Power, and Subjectivity in the Twenty-First Century* (2007). He explains the concept of vital politics by stating that in our current age in which technologies are advanced and do modify human biology and change it, life or death became highly politicized. He used the analogy between vital signs and politics to emphasize that politics now depend deeply on marketing the best for population's health to justify collecting data and interfering in the natural biological functions of human life to regulate it and manipulate it for political purposes.

In relation to HIV and to the mothers living with it in this research, they are governing their bodies by trying to take the medication regularly and looking for any hope for a "cure". In the meantime, they are in the middle of a web of social and political dynamic and subjugating forces, and taking an active reproductive position in giving birth and nurturing their children. The intersection of class, family and socioeconomic dynamics place them at the center of the political based on multifaceted factors among them their biological and gendered bodies, economic and social status. For example, married men tend to conceal their HIV status from their wives and men's families are more likely to know about HIV status of the wife if she is living with it leading to bad treatment from her in-laws (Khattab, 2010, p. 76).

Many women living with HIV and AIDS are widowed and having children after a husband who dies with AIDS (Khattab, 2010). Almost 60 % of women thought that people despise them because they did something wrong or lived “a faulty life” (Khattab, 2010).

For example, the mothers reflected on the announcement of the Armed Forces Device to cure AIDS, each in a different way as I detail in the following chapter, that they had mixed feelings ranging between high hopes for cure and trusting the entity and believing that they are part of a national invention, to mothers who just needed the allowance provided to participate in the experiment. The deployment of the body and risking stopping the HIV medication is an example of the intersecting of sociopolitical forces affecting their everyday. They were fluctuating between frustration from the old management of the National AIDS program to hopes in the new management for the coming year with a sense that they are failed by this precarious and uncertain future to secure medications and sustain their living to nurture their children. They are, also, less likely to share their HIV status with others compared to men living with HIV (Khattab, 2010, p. 101).

Internalized values of neoliberal qualities such as individual responsibility was mainstreamed in health domains and led to new subject formation (Ong, 2008). For example, people might think that HIV positive people brought the disease to themselves by doing unacceptable or “profane ” acts; homosexuality for example was stated as one of the perceived profane acts (Khattab, 2010). Privatizing state hospitals as well as the spread of private hospitals managed by businessmen impose a certain claim that private market ethos are much better than state public ethos in distributing quality services (Ong, 2008). In the market world, the client / consumer is always right. Medical and market authorities manifested in private hospitals render the service seeker more vulnerable. So, when applying the neoliberal reasoning mentioned earlier, we get the economical profit of it manifested in more financial resources to the private hospitals’ management and the self-responsibility of the patient if any misconduct happened that might affect his or her wellbeing.

Transnational governmentality in a neoliberal world restructured the relationships between nation-states and international entities (Ong, 2008). Driven by

market ordering, there is a certain hegemonic claim of linear inevitable progress along with social ordering leading to more civilized clients/consumers/patients (Ong, 2008). In a way or another, global transnational developmental priorities are impacting the national and local ones. Governmental entities now are adopting the transnational developmental priorities as higher goals. For example, in the Investment Economic Conference held in Cairo March 2015, a national development strategy presented by the prime minister was aligned with the sustainable development goals for 2030 advertised by the United Nations.

The aim here is to understand the shifting nexus of setting priorities and power dynamics of transnational governementality and its influence on the local level. It provokes questions such as, what does it take to maintain the funding flowing for national developmental entities? Usually donors set certain calls with specific requirements for giving grants based on specific pre-planned trendy /global issues, what will be concealed or activated in that process? The example of the Global Fund grant and HIV and AIDS in Egypt is detailed in chapter three.

Intersubjectivity

What does it mean to understand the point of view of the other person, particularly, in this context, in telling or listening to stories whether as an act of sharing personal trajectories, in social research or even in counseling? What creates mutual understanding while capturing the picture and imagining what is being told in the articulated narratives? Why do we think that some people can “listen” more than others? How does this act of ‘telling’ contribute to igniting the conatus within to move on in daily life encounters?

The concept of intersubjectivity can provide an understanding of this process of “listening to” and “relating to others”. Alessandro Duranti in his article “Husserl, intersubjectivity and anthropology” (2010) returned to Husserl to trace the understanding of subjectivity. Husserl viewed intersubjectivity as basic human contribution to the art of sociability and as the possibility of being in a place where the other is (Duranti, 2010). It is the quality to interpret and understand others’ points of view. It is necessary to achieve mutual understanding through reflecting continuously on what we hear and interact with (Duranti, 2010). Reflection is an

important pillar to reach a shared social and cognitive understanding of the social and everyday precarious events.

Duranti interprets Husserl conceptualization of intersubjectivity as a vehicle, which is important to reach a possibility of mutual understanding, not necessarily the accomplishment of it (Duranti, 2010). Duranti sees intersubjectivity central to communicative activities related to face-to-face interactions and social encounters, in which different tools, language among them, can give us an idea about the different human conditions. As Duranti states, “intersubjectivity is, first, not a product or an effect of communication but a condition for its possibility. Over time, however, especially within constructivist perspectives, intersubjectivity has come to be seen as something that must be achieved through particular activities including the use of language and other kinds of communicative resources” (Duranti, 2010, p. 9). Hence, it is relational and gives an idea about one’s own self through the reflection process in face-to-face interaction, to put it in Duranti’s words “The importance of the physical presence of an Other for the constitution of the self” (Duranti, 2010, p. 9).

This concept is central for the social sciences; it provides theoretical perspectives for the process of interpreting, organizing and reproducing social life (Duranti, 2010), which happens in ethnographic research especially in interviewing and interacting with the interlocutors. The intersubjective dialogue with the research interlocutors, sharing stories about HIV, motherhood, political events, was central in conducting unstructured interviews. My position was to gain knowledge and understand how mothers’ memories recalled certain life events, ordered them in particular way and linked them with collective social and political lives. The concept is central to counseling or attending group meetings for people living with HIV. For example, health personnel provide information about HIV and living with it for 15 to 30 min right after knowing about being positive if the test is done in a non-governmental organization or national laboratories, not in private laboratories (Khattab, 2010).

In a personal interview with social worker who provides counseling to newly diagnosed people with HIV, I asked her about initial reactions of HIV and how does she provide the information. She said

From what I see, the mothers usually have this question first when they know, are we going to infect our children? So I explain to them how it is being transmitted and know if they have very young children who would need breastfeeding or not. Afterwards, I start telling them about the function of the immunity system and what HIV attacks in the body. I tell them this metaphor that the immunity system is like the army of the body and HIV is the enemy, so we need to make the army stronger by taking the medications and eat well and protect our health, or our army will be weak. I think they understand me better when I say the metaphor and it also goes well with the current talks and events in the country. To my surprise, I noticed that women who are well educated would cry and get a nervous breakdown when they know about the status more than simple poor women who are illiterate. The latter most probably don't know about HIV, so their first concern is to be healthy to be able to take care of their own children. (Personal interview, spring 2015)

The number of men who are aware of the presence of group meetings for people living with HIV is almost double the number of women (Khattab, 2010). Some women who attend the meetings expressed a form of psychological relief while sharing their feelings with other people in the group; hence sociability is a major concern and a spiritual help (Khattab, 2010). In this dynamic and precarious social field constituted through living with HIV and its sociability, the multiple subjectivities of one person can be only reduced to the HIV positive subjectivity. However, intersubjectivity that includes the process of reflection and trading places (Duranti, 2010, p. 9) is central to the ethnographic approach to get glimpses about the human condition. Human condition here is used instead of human nature as a concept, theorized by Arthur Kleinman who argued that it “describes the inherent malleability of lived experiences as it shapes and is shaped by macro-level social, political and economic processes” (Biehl, 2007, p. 29). Hence, the essence of stable or basic innate qualities in the so called “human nature” is at stake. The human subjectivities are continuously mutating within different social fields and throughout their lives, the term “condition” is giving more liberty to be deployed here instead of the static, fundamental and absolute sense of the term “nature”.

Subjectivity

Navigating the subjectivities of the interviewed mothers, through listening to their uttered narratives and participating in intersubjective dialogue and observations, has the ground of this research. Joao Biehl acknowledges the peculiarities of the modern neoliberal world in the remaking of people's lives (Biehl, 2007, p. 1).

Subjects are situated at the interface of multifaceted economic uncertainties, globalization, transitional, and transformational political life to the unknown. Hence, the question is what counts as resistance or collective organizations within dominant structures of power and domination (Biehl, 2007, p. 2). The conceptualization of subjectivities in the book *Subjectivity: Ethnographic Investigation* (2007) edited by Joao Biehl, Byron Good and Arthur Kleinman, provides the foundation on which the present as well as historical series of events meet. This meeting constitutes and remakes the “habitual inner sense of endurance and the creation of new forms of desires that go beyond commercial interests to structure new ways of feeling and living” (Biehl et al, 2007, p. 2).

The editors in the book argue that hyperindividualism and the attention to individual human rights are the consequences of this dynamic process of interacting with multiple forms of power, creating multiple subjectivities (Biehl, 2007). That interaction indicates the agency of the subject to foreclose what is important and at stake in their everyday, amid the eternal processes of societal, political and personal transformation to the unknown (Biehl et al, 2007). Thus creating new forms of pressure and/or resistance on prevalent modes of domination in their surroundings that might lead to a change of any sort (Biehl, et al 2007). The book emphasizes the value of investigating the inner lives of the subjects in social research to manifest the interconnection between subjectivation and transformation of individuals, collective organization, knowledge and structures (Biehl et al, 2007). Moreover, in highly contingent social and political settings as well as the emergence of multiple subjectivities for one human subject, we can say that moral and value systems are not one and for all, rather they are continuously forged and mediated (Biehl et al, 2007). Hence, examining subjectivities provides an analytical lens to recast the work of existing institutions and collective organizations.

For instance, the agency of the mothers is highly manifested in their courage to share their stories with me and with others who are conducting research using different approaches around HIV and AIDS. From reading the stories of people living with HIV in Egypt as literature for this research and encountering the fieldwork with some of them at the same time, I can say there is a sense of awareness on what to tell

or conceal and with whom, and what to articulate in their narratives as I detail in Chapter Five.

Foucault argues that the subject navigates and acts within different and multidimensional trajectories leading to the emergence of multiple subjectivities within dominant discursive practices (Foucault, 1972). The subject constitutes the society as a collective continuously constructing and shaping the circulation of domination and subversion within it, giving birth to the subject as a perpetrator and as a victim at the same time (Hass, 1996). The subject is also a product of multiple ideological institutions that shape her/his ideology, as a directing ideological apparatus, starting from nuclear family, schools, modern communication technologies, religious institutions, medical and governmental institution (Althusser, 1970). To examine the subject formation and influence in both Foucauldian and Althusserian terms, we find that subjects have the agency to influence and shape their surroundings as well as they get subordinated to what they have originally created. As Paola Rebughini states in her article on subject subjectivity, subjectivation “Though caught in the contingency, in the constraints and trials of the situation, the subject always has the opportunity to deal with them using his/her faculty of imagination and creativity” (Rebughini, 2014, p. 3).

Alain Badiou emphasizes the analytical importance of contextualizing the subject within certain structures to understand; as he says “the contemporary subject is void, cleaved, a-substantial, and ir-reflexive. Moreover, one can only suppose its existence in the context of particular processes whose conditions are rigorous.” (Badiou, 2006, p. 3). Badiou’s work in his book *Ethics: An essay on the understanding of Evil* (2001) is of great relevance to my work. Badiou conceptualizes the human subject as “who is capable of recognizing himself as a victim...Because of the status of victim, of suffering beast, of emaciated, dying body...[man is reduced] to the level of a living organism pure and simple” (Badiou, 2001, pp. 10-11). For Badiou, this unites the human as a thinking animal with other animals; however, it makes the human stand out in its potential to resist, especially in dire situations (Badiou, 2001). Badiou argues further that human subjects do great efforts to be “immortal” and beat “mortality” when faced with disasters or appalling circumstances, as he articulates it “ as an almost incomprehensible resistance on the part of that, which, in them, does not coincide with the identity of victim.” (Badiou, 2001, p. 11). He adds:

However, how can humans beat immortality when they are threatened? Badiou's answer to this gave rise to what does it mean by a political subject. Politics for Badiou can be understood as "collective action, organized by certain principles, that aims to unfold the consequences of a new possibility which is currently repressed by the dominant order" (Badiou, 2008, p. 31). Hence, the mere efforts to join the collective and join a platform that provides sameness of some sort creates a political subject and gives a sense of fulfillment and acknowledgement of producing something that can relate beyond the individual subject (Badiou, 2001).

My research thus situates the subjectivities of living with HIV and how they relate to being a mother, a woman and an Egyptian. The analysis of the documents and focusing on public collective events reveals an aspect of living in Egypt from 2011- 2015. It focuses on practices and reflections uttered and enacted by the interviewed mothers that can make the use of the construct of political subject as an analytical category possible, starting from the decision to give birth and reproduce as narrated in the stories of the mothers. The ways they look at their children and motherhood are means that sustain their own existence. One of the mothers who was married to an HIV positive man said:

My husband dearly wanted a child. We went to the National AIDS program and consulted with the doctors to have a healthy child and we did. One and a half year later, my husband died. However, he was the happiest man on earth for the year and a half that he lived with our son and he was taking care of all the little details of nurturing our child. It was the happiest time of my life. Although, after my husband's death I was suffering from his loss and the burden of raising the child, but I moved to my family's house to have more people to take care of my child with me (Maha, Spring 2015).

Other practices, indexing the political were manifested in joining the collective of group meetings of people living with HIV (support groups), their awareness of the funding opportunities related to HIV and AID and from where the treatment and medications are secured, and finally in how the mothers reflected on the work with different non-governmental organizations. One of the mothers indicated that her philosophy in life has changed and she became more proactive in taking decisions like divorcing her husband or securing a job to sustain her family. Another mother uttered her realization that they are sometimes being used as a category of

people living with HIV to get funding for different projects related to HIV in the development sector. She said that the image and the presence of an HIV person and the announcement of the device that would cure HIV are examples of that, especially focusing on more “innocent” categories of HIV and AIDS people than others. Innocent here is meant in the sense of contracting HIV from more socially acceptable sources like a husband or blood transfusion. The mothers were aware of the way HIV positive people are being represented viz.-a-viz. people who live with Hepatitis C in Egypt. There is also a general sense of idleness and repeated quote with defeatist vibe in it saying: “most of Egyptians have Hepatitis C.” In other words, it is obvious that the creation of HIV positive subjectivities is assisted by the same people who are working to eliminate its stigma and prevent it from progressing in big numbers in the country.

The way in which HIV is discussed makes it peculiar and may even be more stigmatized and “othered.” Here, analytical awareness of how the HIV category is being used is often distant from the dominant discourse of developmental work. At the same time, the most often used rationale is for raising awareness and disseminating scientific information is eliminating the HIV stigma, although raising awareness is confined to health information only, a conviction held even by people living with HIV (Khattab, 2010). This leads to reducing the whole issue into wrangles over a scientific debate and overlooking the social, political and economic concealed arguments that lie beneath. I find the quote from Alain Badiou book, titled” *Saint Paul: The Foundation of Universalism*, 2003) relevant:

Each identification (the creation or cobbling together of identity) creates a figure that provides a material for its investment by the market. There is nothing more captive, so far as commercial investment is concerned, nothing more amenable to the invention of new figures of monetary homogeneity, than a community and its territory of territories. What inexhaustible potential for mercantile investments in this upsurge—taking the form of communities demanding recognition and so-called cultural singularities—of women, homosexuals, the disabled, Arabs! And these infinite combinations of predicative traits, what a god-sent! Black homosexuals, disabled Serbs, Catholic pedophiles, moderate Muslims, married priests, ecologist yuppies, the submissive unemployed, prematurely aged youth! Each time, a social image authorizes new products, special magazines, improved shopping malls, “free” radio stations, targeted advertising networks, and finally, heady “public debates” at peak viewing times (Badiou, 2003, p. 11).

Maternal Subjectivity

Familialisation was attacked by feminist critiques that theorized mothers as “objects of their own babies and family needs rather than people in their own rights” (Hollway, 2001, p. 4). Wendy Hollway reviews the theorization of motherhood and maternal subjectivity in her article *From Motherhood to Maternal subjectivity* (2001), acknowledging that in all claims about motherhood, there is usually an inclination towards one model fits all. Those assumptions about motherhood are circulated within the multiple structures that women live in from family, media; and even advertisement disseminating models of how good mothers should look like (Hollway, 2001). Hollway expresses that structures and institutions as well as practices assume “a clear cut and uniform effects” of mothering, hence, in poststructuralist conceptualization, mothering would seem alike an object of government regulation (Hollway, 2001, p. 2). Feminists’ critiques have raised the issue that mothers are autonomous subjects with rights, and feminists psychoanalysts have indicated that children need a mother who is autonomous and fulfilled (Hollway, 2001, p. 2).

Hollway argues that different dynamics shape women’s positions in motherhood within various discourses; hence, she opts for “unconscious intersubjectivity” in psychology as an approach to examine maternal subjectivity rather than motherhood as a regulated site (Hollway, 2001, p. 7). Motherhood exclusively focuses on women and indicates that mothers are the objects of the needs of their own children (Hollway, 2001). Hence, maternal subjectivity, provides more space, as an analytical category, to examine how “women who are mothers are not only mothers” (Hollway, 2001, p. 8). Hollway acknowledges that there are multiple forms for caring for children, ranging from taking the responsibility solely as a mother on her own to the collective caring for children in some countries in Africa for example (Hollway, 2001). Hollway talks about the fact that it is difficult for mothers to express their confused feelings about their babies, if they had any, to the public (Hollway, 2001). Hence, a tremendous load would be felt by them, especially that the dominant discourse of motherhood emphasizes only the good side of having babies in terms of love, warmth and fulfillment only and no mention about maternal

ambivalence. Thus, the internal struggle felt within mothers remains concealed to fulfill certain agreed upon images of pure sacrifices and self- sacrifice.

Hollway acknowledges the realities of maternal work in nurturing children that extends beyond the relativism and theorization of maternal subjectivity that forms certain universal work requirement (Hollway, 2001, p. 9). She extends this concept of universal maternal work that was originally quoted by Ruddick, in her book *Maternal Thinking: Towards a Politics of Peace* (1989) to embrace the unconscious emotional work of mothers that is infused with feelings of love, hate, obligation, envy, and guilt, among others (Hollway, 2001, p. 9). Hence, she is more inclined to use intersubjectivity as a model of talking about children's emotions affecting the maternal subjectivity and in documenting accounts of maternal subjectivity, that should embrace the interconnectedness of the meaning, fantasy, social relations and struggles of the maternal (Hollway, 2001).

Pamela Downe lists in her article "Motherhood and HIV/AIDS as Sites of Actions" (2011) the claims of the absence of feminist scholars from debates around HIV and AIDS in its early years (Downe P. , 2011). She quotes Paula Treichler and Catherine Warren (1998) saying that "feminism was most certainly not in the air – or anywhere else, it seems – during the early years of the HIV/AIDS epidemic" (Downe P. , 2011, p. 7). Downe presents the argument of Daphne de Marneffe in her book titled *Maternal Desire*, which explored the interaction between feminism and motherhood and claimed that feminism offered little of an understanding of motherhood and maternal emotions. As Daphne argues feminists had changed the perception of gender relations, however they lacked innovative ideas on how to achieve this while you are a mother and keen on spending time with your child (Downe P. , 2011, p. 9).

Downe did ethnographic research with HIV positive mothers in a clinic in Canada, she admired their "powerful and grounded approach to deconstruction that they adopted in their daily lives in order to engage in a self-advocacy as mothers living with HIV. The research participants in this study draw moral force to deconstruct dominant ideals of one-mother 'perfection' and assert their own maternal rights" (Downe P. , 2011, p. 10). Downe found that the mothers challenged the

“idealized caricatures of motherhood” that constrain the maternal experiences of marginalized women. (Downe P. , 2011, p. 12).

Downe argues that in our contemporary times many feminists are seeing motherhood as a site for individual and collective activism. This is being manifested, as a clear sharp focus, for mothers who are living their lives under visible constraints such as HIV/AIDS, poverty, addiction (Downe P. , 2011) She concludes, ”In these often dire circumstances, motherhood (as an institutionalized category) serves as the primary site of political action” (Downe P. , 2011, p. 10).

There is a link between the political subjectivity of the research interlocutors and their maternal subjectivity, in which their maternal work with its set of meanings and practices, is political work. “The personal is the political” was the slogan invented by feminists critique regarding the liberal theories of public-private split (Pateman, 1983, p. 282). Carole Pateman provides a record in her article titled “ Feminist critique of public private dichotomy” (1983) about the liberal theory of public private split, in terms of liberating people from the control of government and minimizing their presence in private realms of life. She elaborates that the adoption of this rationale of thinking and constituting dichotomies are not helping the women in their everyday lives (Pateman, 1983). She argues that liberal theories of governance did not provide a resolution to patriarchic practices in the private sphere, for example; hence women remain subordinated (Pateman, 1983). She states that private and public realms of life are co- constitutive and splitting them as two separate arenas emphasizes dominant discourses (Pateman, 1983).

The mothers in this research, as we will read, were trying to change their own personal lives, desiring a less precarious future for themselves and for their children. One of them divorced her husband, as he did not fulfill his role on the emotional and economic sides. That was made possible after having the Khola’a Law that granted her that right. The boundaries between what they practice in personal /private life and the public sphere are imaginary, as they both infiltrate their everyday practices constituting their empirical realities, in which, maternal work of fulfillment is one of them.

I listed the literature above to give an idea about concepts of motherhood and maternal subjectivity, considering the multiple power dynamics in which women and mothers function. It was my readings along with personal daily processing of what does it mean to be a mother, especially that I have a 5 years old child. Being personally distracted between different forms of mothers in different generations, I was questioning what constitutes a “devoting” and “successful” mother. Guilt feelings and anxiety of thinking about my child were present while studying, working or even socializing. And on the other hand, I had the feeling of missing out on something while spending time with my child. I understood that I had the privilege of reading about different perspectives about the notion of motherhood. However, I felt that there is something missing in terms of the reality of having a child that I am supposed to be his mother. Hence, this particular dimension of the fieldwork was emotional and subconsciously led to the shared intersubjective dialogue, accompanied by reflection on my own story of having a child with present and future aspirations of nurturing him, and most importantly to deal with the continuous feelings of guilt.

Chapters’ Flow

The chapters are constructed around the stories of the mothers situated within the analysis of documents, national media press and public events. The second chapter starts with overview of Egypt as the site reviewing incidents related to using morality as an apparatus for dispersing control to get an idea about the context of the research topic. Then the tales of encountering the complete cure device that was announced by the Armed Forces are presented. The third chapter, discusses governing care and treatment with sections about reaching out for treatment in which the journey to get treatment is presented, how the treatment is being secured and the incident of misconduct in managing the Global Fund grant is discussed. The fourth chapter present the stories related to testing for HIV and NGOs work on prevention to reduce the harm and prevalence rate of the virus. The fifth chapter deals with mediating the social through stories of hope and loss as well as encountering paths of socialization and the engagement of some of the research interlocutors in outreach work.

Chapter Two: The Ethico- Political deployment of HIV

Egypt as the site

The next few pages I give a brief account of select events that were in the political sphere and which are relevant to the main question of the research. Techniques of accumulating political power through different paths conjure at the end and constituting the political, such as lack of freedom of speech, othering any voice that has different points of view, creating a state of exception through measures for combating terror and terroristic attacks. For example, different laws address the social, the economic as well as the personal that are passed without consultation and presented as a one-man show. Amidst this, people are being killed in large numbers and homicide charges are not applied to the killers if they are part of the security apparatus. In addition to the circulation of the long-lived conspiracy theories propagating that Egypt is targeted from outside, simultaneously using nationalism to recall the category of Egyptian Identity and Egyptian moral citizens. The commodification of people and national resources through techniques of including or excluding certain people and the emergence of the category of honorable citizens '*mowaten sharif*' do contribute to the constitution of the political.

HIV related Numbers

Since its identification in early 1980s, HIV has affected more than 60 million people all over the world (UNAIDS). Currently, around 35 million young people are living with HIV (UNAIDS). In Egypt, the number of people living with HIV as estimated by UNAIDS and WHO contradicts the number declared by the National Aids Program affiliated with the Egyptian Ministry of Health. Generally, Egypt has a low rate of HIV prevalence in the general population; currently below 0.01 percent or 4,781 HIV positive cumulative cases of these 3,746 are Egyptians and 1,035 foreigners (National AIDS program NAP global AIDS response progress report for 2012). Currently, 2,471 Egyptians are known to be living with HIV; among whom 388 (15.7 %) developed AIDS (National AIDS Program, 2012). However, UNAIDS and WHO have estimated the number of people living with HIV in Egypt to be around 11,000 persons in 2010 (National AIDS Program, 2012).

Civil society groups conducted research to examine the doctors' knowledge and attitudes towards HIV. A study titled "Combating HIV/AIDS related Stigma in Egypt: Situation Analysis and Advocacy Recommendations" shows that doctors need to be more educated about the topic. Meanwhile, the results in that study show that there is a gender difference in stigma and discrimination related to HIV among the health care personnel. Furthermore, the gender of the practitioner affects the way they deal with persons diagnosed as HIV positive (EIPR, 2007).

During the Mubarak regime, civil society was regulated and closely monitored, and after his ousting in 2011 and the change of government and presidents, the situation is still not any better. The scrutiny over civil society led to dissolving almost 400 NGOs in March 2015 and many NGOs were classified as linked to the Muslim Brotherhood, which was categorized as an "outlawed organization" in late 2013.² Non-governmental organizations working on HIV and AIDS provide prevention services to people who are identified at high risk, like people who inject drugs, men who have sex with men and female sex workers. However, most services working on treatment, confirmatory blood testing and medical care are supposed to be provided by National AIDS program at the Ministry of Health (MOH) (National AIDS Strategy 2015-2020).

Morality and the discourse of control

Morality apparatus is deployed for gaining social support and building social capital through media outlets and state institutional declarations. The Circulation of the speech between people claims that by regaining the moral identity of Egypt and guarding its morals and conservative values, the country will be able to transition peacefully to stability. Issues of the presence of western morals and western agendas that affect the stability and security of Egypt are widely used by the current Egyptian president and his government and were used before by the previous president in Egypt post 2011. I went through different media outlets to provide an idea about the context of the research, which is Egypt post 2011. Currently, Egyptian authorities are conducting raids on political activists, civil society NGOs, as well as oriental dancers and homosexuals. Since July 2013, there are over 40,000 political prisoners and detainees especially after issuing the Egyptian protest law. Security forces killed more

² <http://www.madamasr.com/news/ministry-investigate-ngo-over-awareness->

than 1,500 persons and the notion of war on terror was mainstreamed and celebrated by media outlets. Noting that Egypt's president El Sisi has been very active in issuing sudden laws that didn't go through the regular path of law legislation through the parliament making him a pioneer in all the history of Egyptian presidents in the number of laws he issued since he was elected as a president (Egypt Independent Newspaper retrieved in 2015).

The social discourse on HIV and AIDS is influenced by media outlets and by the secrecy around sexual relationships. In the case of Egypt, movies in the 1990s were featuring people infected with HIV as promiscuous individuals. At the same time they disseminated incorrect information on how HIV can be transmitted, which contributed to the fear and stigma around the disease. A clear example of that is the popular movie in early 1990s called Love in Taba (*el hob fi taba*) In which one of the main characters was a physician who got involved in a sexual encounter with a foreigner in the area of Taba of South Sinai. The doctor covered his hand upon greeting people in order not to transmit the virus, which was a powerful image that was embedded in people's imagination and enforced a misconception that HIV can be transmitted through physical touch. That movie has enforced the stereotypical thoughts related to HIV at least in two dimensions. First, through showing the physician who is supposedly equipped with knowledge and represents an authoritative figure covering his hand to prevent transmission of disease agent. Second, through presenting HIV as some epidemic that only comes from outside and through illegitimate sexual encounters with "foreigners" stimulated the conspiracy theory and confirmed the idea that HIV is a Western disease.

In 2011, the broadcasting of a movie titled "Asmaa"³ was a worthwhile success in changing how HIV is addressed in the movies' world. The movie presented a story of a woman in her forties living with HIV and trying to go through a surgical operation, yet she faced refusal from doctors upon knowing her case. The movie showed the archetype of a civil society worker facilitating a support group, a TV presenter for a talk show who is striving on media scoops in his career and wanted to host the main character Asmaa. In between, Asmaa decides to go on air with the TV presenter to talk about her story and secure a medical treatment. The internal struggle

³ <http://www.imdb.com/title/tt1826603/>

of Asmaa and the flashbacks of her life were presented in the movie in a way that uncovered to the public what is going on in the life of an Egyptian woman living with HIV. The general public received the movie with great viewership and was presented in big cinemas all over Egypt and discussed in workshops talking about HIV and AIDS. However, Asmaa was married, had a 16 years old daughter and was living with her father after the death of her husband. I would say, that although the movie presented living with HIV in an Egyptian and empathetic way disseminating correct medical information and the internal struggle of living with it, nonetheless, the idea of an innocent victim who got HIV through the “legitimate” act of marriage and living with her father and daughter was prevalent. It is in a one way or another a step towards realistic and informative presentation of the HIV and AIDS issues in Egypt. It acted as a start, a culturally appropriate one though.

Asmaa, ends the movie with a quote that was provocative, “If I will die, I will not die of my disease, I will die from the disease that you have” in a clear message that the attitude towards HIV from the people and the medical doctors who refuse to treat her, will kill her. In short, the issue that stigma towards HIV kills was emphasized.

There is an example of a public TV show that I find relevant to the research and my interlocutors highlighted its popularity and effect. The TV channel started with advertising the show as “Watch the bold Mona Iraqi reveals in a series of investigative episodes the secret behind the spreading of AIDS in Egypt” as a trailer for their programme, which was presented as a journalistic scoop and a tie-in with World AIDS Day in the first week of December 2014” (The Guardian, 2014).

In this event, 26 men were arrested and tortured after a raid on a Cairo old bathhouse charged of homosexuality in Egyptian laws under debauchery. It gained high visibility in national and international media. The detainees reported that they were tortured and humiliated at the police station of Azbakeyia. They were released January 2015, when their reputation were ruined and their lives destroyed to the point that one of them tried to burn himself alive in February 2015 saying “I work in a restaurant” he told Al-Watan newspaper. “I’m harassed constantly in my workplace by the words of the people and the looks in their eyes” (Long, 2015). He said that he could not survive the immense emotional stress for the trauma, social stigma and

discrimination that he experienced in the period during detention and after his release. In addition to that, he elaborated that his family controlled his movements and tried to keep him from leaving the house and one of his brothers accompanied him everywhere. In addition to that, he is being treated now in one of the largest public hospital in Cairo and he complained of neglect and mistreatment. One of his defense lawyers pressed a lawsuit against journalist Mona Iraqi, the TV presenter, and concluded, “the man’s suffering is due to the narrowness of the society point of view” (Long, 2015). The hostess of the issue was sued and the program stopped after the involvement of civil society and other national media press in exposing the cruelty of this act.

The raid on the public bath and arresting all the men inside was captured in the TV show as a measure to prevent the transmission of HIV and AIDS into the public (*El Mestakhabi* (The Hidden) TV program, 2014). The presenter (Mona Iraqi) hosted the head of an NGO called the Egyptian society to fight HIV and AIDS and designed the show as an attempt to present to the public the roots of HIV in Egyptian community. The show hosted also the manager of National AIDS Program, who warned against spreading rumors that ruin people lives and that strategic actions should not be based on scandals or assumptions when the TV hostess asked him if he knew about or has taken action against places for group homosexual sexual encounters. The historical public bath and the tradition of using public baths has been in Egypt since centuries is being used now to destroy the lives of its customers, disseminate fear and uncertainties as well as entertain the public and distract them. Many people living with HIV expressed that this act and such TV programs would further aggravate the stigma and the discrimination that they are suffering from in addition to jeopardizing their safety. The TV presenter was sued and charged with 6 months in absentia in December 2015 and the TV show was stopped.

In the Egyptian social life, there is a prevailing norm of the taboo of talking about sexual life and discussing what constitutes safe informed sexual encounter. However, in gendered settings, the talk about sex can be more open considering variations by class, age and socioeconomic status of the neighborhood. In this context rumors play a major role in disseminating misinformation and circulating what is considered as private, thus shaping the public imagination so to speak. In that case, the vernacular around sex talk and sexually transmitted diseases would amplify the

morality and norms rhetoric and fortify perceptions that discriminate against people living with the virus (Smith et. al.1999). The incidence of the investigation for the NGO in the following chapters can be one of many examples.

To Care to have a Healthcare system

Healthcare workers are part of the society. They are products of its culture and structure. Hence, they are influenced by the social discourse on HIV taking into consideration the kind of services that they are supposed to provide, their personal background and the context and place in which they operate. The perceptions of health care providers of people living with HIV is highly crucial as they are supposed to be providing the medical care and support needed and usually they are the first line that a person living with HIV would visit to ask for help and support. Additionally, people who are marginalized are less likely to obtain proper health care services.

I followed a facebook group consisting of more than 6000 members of medical doctors and health activists who are trying to provide a platform for exchanging national documents related to the medical field like the code of conduct and new laws related to health insurance and new medical cadre strategies. The group is titled Health Sector reform (*islah el keta'a el sehie*)⁴. One of the issues that doctors are struggling with is the chaotic process when reporting a work-related infection and the low payment they receive as compensation (19 Egyptian Pounds per month). There are efforts to raise the monetary compensation and the medical syndicate issues guidance and statements related to what should be done in case of getting infected. The Ministry of Health and the Medical Syndicate are not always on the same side in terms of working towards the rights of doctors and patients. The medical syndicate adopts a rights-based language and has raised many issues related to the health system in Egypt.

Egypt is a lower middle-income country and the health system is struggling with insufficiency of the allocated national budget for health (between 3% and 5% of the national budget) and proper health informatics. An estimate of the number of doctors who are actually working in Egypt was last measured in 2009 at 2.83 doctors

⁴ <https://www.facebook.com/groups/eghreform/>

per 1000 persons (this figure includes generalist and specialist medical practitioners) (tradingeconomics website accessed 2015).

Medical doctors are suffering from low monthly salaries, and the medical syndicate is working to secure the rights of medical doctors especially in the case of work- related infection. On 12 November 2015, a doctor got infected with HIV while fulfilling his duty, but then the hospital management did not renew his contract. His story was shared on national media press⁵. The struggle of the medical doctors and the patients is interlinked. Starting from the lack of measures related to securing the work place for doctors to be of high quality assuring the low rates of work related infections to low salaries and the increase of out pocket spending on health in Egyptian society. The medical syndicate is debating the new health insurance law in the meantime, the ministry said that it will be published soon. This issue of the health sector in Egypt and the co-constitutive failure of securing patients' and health officials' rights needs another research. I talked here briefly about a small dimension that affects HIV and AIDS care and medical support to a great deal.

⁵ <http://www.vetogate.com/1897163>

Introducing the device



The device and Ibrahim Abdelaty ⁶

“I swear you won't find an AIDS patient in Egypt anymore. I swear you won't find a Hepatitis C patient anymore. We won't import drugs anymore,”⁷

Egyptian Armed forces spokesperson in the official press conference,
23 February 2014

Egypt has less than 0.1% HIV prevalence rate and more than 15% HCV prevalence rate (Causing Chronic Hepatitis C) the largest HCV rate in the world⁸. On 23 February 2014, a press conference was held by the Egyptian Armed Forces to announce a device that it claimed would cure HIV and HCV. The device depends on electromagnetism mechanism to detect and treat HIV and HCV. The device included part called C-Fast which was initially advertised by the Egyptian doctor Gamal Sheiha working on hepatitis C. C-Fast itself claims to be using the same technique used in detecting bombs (by the Iraqi military at check-points) depending on

⁶ Still photo from short documentary was shown in the armed forces press conference on State TV of Physician on (the right wearing shirt) and Major General Ibrahim Abdelatti (wearing medical doctor white coat) with "C-Fast" device. Source : Ahram English website.

⁷ http://www.madamasr.com/news/cc-complete-cure?_ga=1.2702512.1057127989.1443283483

⁸ <http://www.cdc.gov/mmwr/preview/mmwrhtml/mm6129a2.htm>

electromagnetic mechanism through detecting a specific frequency emitted by infected liver cells. A radio Ariel was attached to a plastic box containing unknown mechanisms of how it actually works or what is inside the plastic box.⁹ The former Egypt presidential adviser Essam Heggy (during the governance of interim Egyptian president Adly Mansour) opposed the Case of Complete Cure device in Egypt. In national press media, he argued that he has papers proving that the devices were ineffective and that he had presented them to the Interim President.¹⁰ In January 2015, Khaled Abou Bakr, a lawyer, filed a lawsuit against army official and medical team who announced, promoted and participated in the clinical trials of the device¹¹. His published complaint addressed to Egyptian General Prosecutor stated that the Armed Forces conducted clinical trials with the patients and failed to deliver the promised results by the publicly announced deadline of 30 June 2014. Gamal Al-Serafy, Director of Egypt's Armed Forces Medical Department responded that the Armed Forces required more time for repeating the clinical trials.

The former president of the National Research Institute, Hani El Nazer stated that the army's medical committee would announce the results of new tests in May 2015¹². Again, the promises were not fulfilled. The lawyer demanded compensation for the people who had participated in the unsuccessful trials, forgoing their HIV treatment and family responsibility during that duration.¹³

The Medical Syndicate strictly opposed the device and the propaganda around it. Their statement published in Egyptian newspapers stated: "The Doctors Syndicate has started investigating doctors who took part in this crime, and is considering the necessary means to hold accountable everyone who took part in the crime of misleading the Egyptian people. The device has not been through the necessary stages of scientific hypothesis... laboratory experimentation, animal testing, then human

⁹ <http://www.theguardian.com/science/blog/2013/feb/28/hepatitis-c-detector-sells-hope>

¹⁰ <http://english.ahram.org.eg/News/95121.aspx>

¹¹ <http://www.dailynewsegypt.com/2015/01/05/lawsuit-targets-army-officials-claiming-hiv-hepatitis-c-cure/>

¹² <http://english.ahram.org.eg/NewsContent/1/64/122055/Egypt/Politics-/Doctors-Syndicate-to-investigate-doctors-who-endor.aspx>

¹³ <http://english.ahram.org.eg/NewsContent/1/64/122055/Egypt/Politics-/Doctors-Syndicate-to-investigate-doctors-who-endor.aspx>

trials, after which it should be presented at conferences to discuss efficacy versus risks. Finally, only if its efficacy is established, should the treatment be provided to the public” (1st of February 2015 Ahram English newspaper website).¹⁴

Dr. Amr El- Shoura, a member of the doctors’ syndicate council expressed his concerns that doctors under the auspices of the military would be protected from any measures against them because they would have to be referred to a military court. However, other medical doctors involved in the clinical trials and announcement would be investigated by the syndicate and face penalties including permanent suspension from their medical practices¹⁵.

Hope and its politics

Exploiting the hopes of people suffering from chronic illnesses is not new. Homeopathy and herbal medicine to cure HIV and cancer, for instance, have long been exploiting the hopes of people in search of cures.¹⁶ In his analysis of South African HIV discourse Hoad (2005) notes the South African government endorsement of Virodene, a drug that the government in 1998 claimed it might cure HIV and AIDS (Hoad N. , 2005). It had a toxic industrial solvent banned for use by humans by EU, US governments and China called dimethyl formamide (Hoad N. , 2005). The drug was tested on humans in Tanzania and the company, which made the drug, was not sued by any governmental entities. Three years later, the high court in Pretoria refused multinational pharmaceutical companies exclusive drug patent rights and encouraged production of much cheaper generic Antiretroviral drugs. However, later in same year, the government refused to supply pregnant women with Nevirapene, which is an endorsed drug by World Health Organization that limit mother to child transmission under this high court order (Hoad N. , 2005).

People living with HIV were not provided adequate HIV treatment and were caught in confused and sudden governmental decisions that affected their lives and

¹⁴ <http://english.ahram.org.eg/NewsContent/1/64/122055/Egypt/Politics-Doctors-Syndicate-to-investigate-doctors-who-endor.aspx>

¹⁵ <http://english.ahram.org.eg/NewsContent/1/64/122055/Egypt/Politics-Doctors-Syndicate-to-investigate-doctors-who-endor.aspx>

¹⁶ <http://www.theguardian.com/science/blog/2013/feb/28/hepatitis-c-detector-sells-hope>

the lives of their children. The government blocked the international funds for treatment and refused to disperse 72 Million US dollars for HIV treatment to a Kwazulu from the Global Fund (Hoad, 2005). In 2003, drugs were held in the stores of the Ministry of Health and doctors were forbidden from distributing them (Hoad, 2005). Consequently, infection rates increased 5 times since 1991 to reach 25 % in South Africa, while arguably going down in other Sub-Saharan countries (Hoad, 2005). Arrogance, confused planning and not prioritizing the needs of the people living with HIV affected the people dramatically in South Africa during that period.

In the aforementioned press conference the Armed Forces announced that they had discovered the device that detects and cures HIV since 2006, but they did not announce it until it also detected HCV. The press conference was attended by the Interim President (Adly Mansour) and the then Egyptian's Defense Minister El- Sisi (Egyptian president since 2014) but without the presence of Dr. Maha Al Rabat the former Minister of Health (was replaced by Dr. Adel Adawy by the end of February 2014, though there is no evidence that the device incidence has any relationship with her replacement). Dr. Adel Adawy stated in an interview following his appointment on the MBC TV channel that he was part of the medical team that has worked with the Armed Forces three years ago in the process of inventing the device. He declared that the device is proven efficient and effective in curing the patients¹⁷).

Women tales about the device

Aside from the unprecedented way of announcing the supposed scientific achievement, I was interested to examine how my interlocutors perceived the news. The news exceeded its scientific claims and people's reactions were aligned with their political affiliations, thus divided between supporters and opponents of the Armed Forces. The Armed Forces in turn did not share any information on how the device was to work, or its side effects. International agencies and the Egyptian National AIDS program kept silent and did not clarify the issue even to the people affected by the disease.

One of the outreach workers that I interviewed remembers the time of announcing the device as a period of confusion:

¹⁷ <http://www.madamasr.com/news/health-minister-worked-hiv-and-hepatitis-c-cure>

We were in a confusing situation and we didn't know what to tell people who asked us. People living with HIV and with HCV were checking with us if it is true that our armed forces found a cure. The situation was vague and if we claimed that this is not true, some people would respond that we are not faithful to our army and the army will not declare such an achievement unless they are sure. Some said you might be a brotherhood and envious. The truth that we kept discreet and cautious about our position regarding the alleged cure till it got clear and people knew it was not true. HCV cure was already there and people started their treatment regimen but there is no cure for HIV as announced. The problem was in polarizing our response and taking it into political stand whether we are with the army or against it. (Personal interview, Spring 2015)

Three out of the five mothers interviewed shared their experiences and reflections regarding the event of announcing a complete cure device that was developed by the Engineering department in the Egyptian Military. Two of them participated in the trials of the complete cure device and one did not participate. They were eager to express their opinions whether they were part of the experiment to try the device or not. The other two non-participating, mothers expressed their hope and faith in the effort of the army to come up with a cure. The words of one of them were “Insha'Allah, they will find a cure to AIDS as they did now for Hepatitis C”. (Personal interview, Spring 2015)

Maha, participated in the first trial of the device and stayed for three months in the *Homi'yat Abasseya* hospital (fever hospital) where the trials took place. This Cairo hospital is also one of the sites where HIV medications are dispersed on a monthly basis to people living with HIV. During my initial conversation with Maha, her voice was monotonous and tired. Maha said “I can tell you the needed information about my HIV status, I have attended HIV related focus groups and know what people usually ask us for. I will tell you what you need to know”. However, Maha's voice became more vibrant once we started the topic of the announced device. She learnt about the device from a paper-advertising piece and from officials in National AIDS Program before announcing it to public. Maha said with a more enthusiastic voice:

Did you know that I was one of the first people who tried the device, I was even invited to the press conference on TV when they announced it to the public. They collected us and said you are cured and we will announce the device on public. I was convinced that I was cured, may be my high hopes and back then trust that made volunteer for the first trial of the device. I told

myself, you have nothing to lose by trying the device. If it worked, I will be cured. I left my 3 years son with my aunt and my sister who took care of him for the three months the duration of the clinical trial. I also felt that I was participating in a high level national achievement that needed all these men in military suits and this secrecy. We were after the revolution with positive speeches and aspirations of new Egypt. (Maha, Personal interview, Spring 2015)

Then Maha described the daily routine in the hospital room:

We gathered in the hospital outside garden waiting for each one of us to meet responsible person of the device, Dr. Ibrahim Abdelaty. I knew later on that he is not a real doctor, and that he treats people with herbal medicine. All of us were living with HIV. When it was my turn to meet Ibrahim, he asked me how did you get infected with the virus and for how long you have been living with it. I told him that I was married and my husband passed away from the virus and I have a child. I was accepted to be one of people going through the clinical trial. When I was admitted to start, I had a room in *Homi'yat* hospital and they were mostly military doctors and soldiers around us. They said that those rooms were rented from the management of the hospital. I stopped my HIV medication for the trial period as requested and was allowed to eat only certain food provided by them. No meat at all. Every day we go to try the device. I lay down on a bed next to big device and the needles first were inserted in neck and all blood go through the device and return back. It looked like one of the renal dialysis devices that I saw before in hospitals. I used to be feverish and exhausted. Dr. Abdelaty would give us daily pills in small brown glass container written on them in Arabic wishes of recovery. No medical name on those pills. He would ask us everyday how we are doing and confirms that we are getting better as he examined our blood tests and HIV is being eliminated from our blood. Deep inside, I didn't like seeing him, he was not smiling and very gloomy. (Maha, spring 2015)

Maha described that the presence of all those military suits was contributing to two contradictory feelings. In a way it was enforcing her sense that she is part of a big thing for her own good and that of her country. At the same time she hoped to see more "white coats". She said that most of the doctors were part spouses to military officials. Maha remembered her colleague in the experiment named Sara that passed away at the end of the three months. She remembers their need for a dentist, the dentist who came was himself living with HIV and wanted to join the clinical trial and offer his services. Reflecting on her experiences, she observed:

Until now, when I remember how I was convinced as well as thinking that I got better and my body is being cured from the virus, I feel betrayed but what shall I do. I was relieved after the end of the clinical trial going back to my

child. Who knows, I could have died in those three months. I was suffocating in that room for three months not allowed to go out of the hospital and my psychological state was very bad. (Maha, Spring 2015)

In contrast to Maha, Amal was suspicious about the lack of clarity about the entire process of treatment from the outmost:

I felt that it is a fraud; it was a gut feeling. Maybe this thought resulted from what I have witnessed in the past years since 2011 and all the political events. When I heard about the device, I was skeptical. The main reason was I was sure that if anything went wrong during this treatment announced by the army, no one will be accountable (*Yet'haseb*). How can you put a military person under trial because of AIDS cure failure? You can't put the Suit "*Badla meery*" under trial. Moreover, I have three children so, how come I can leave them for three months and be confined in a room in a hospital for the clinical trial? I know that my HIV medication is helping me to move on with my life and provide care for my children. I hope for a cure, however I made peace with the idea that there is none. It took me time to reach this and now I look forward everyday to have the health to the day I see my children educated and married and have their lives. (Amal, spring 2015)

Sama, on the other hand, went with her friend who is also living with HIV to the hospital to interview for the opportunity to participate in the second round of the clinical trials of the device. She went primarily because of the 1000 Egyptian pound pay to trial participants, though she was not sure if his was per month or for the entire trial. Nonetheless, she arranged for someone of her family to take care of her almost 8 years old child. In her description of waiting for the interviews and the interview itself, Sama recalls most vividly the authoritarian relationships that structured the encounters:

I waited so long in the hospital garden, it was a warm day and we were tired. Finally we were able to enter and I heard a nurse telling a young person standing with us, you look gay don't tell Dr. Abdelaty that you got HIV from sleeping with men, he will not let you enter the clinical trial. When I entered and was standing in front of Dr. Abdelaty I was stressed. His looks were not encouraging and he rarely raise his face from papers he is looking at. He asked me about my age and then said directly, how did you get infected with HIV. I told him directly from my husband, I am married. Dr. Abdelaty then asked me, how did you husband get infected. I answered that he has an addiction problem and injects drugs. Right after, Dr. Abdelaty told me, go tell your husband to get clean and stop drugs and then come together for another trial. I was disappointed and felt humiliated. But when I knew what happened to some of the people who were waiting with me, I felt more at ease and that other people were treated in horrible way. For example, he asked one of the women how did you get the virus, she said I don't know. His reaction was

dismissing her saying that she is a prostitute who slept with many people and doesn't know from where she got the virus. Another woman was wearing a Nikab covering her face. Dr. Abdelaty asked her to remove it and she refused. He dismissed her as well saying we are not curing ghosts like people here. The last one I knew about was not wearing cloths that he liked and he told her what are you wearing is not suitable and get out. As if he is holding a ruler, morality ruler (*mastarra*) that he used to measure morals of the people entering the trials by it and dismiss what he thinks are immoral; as if some of us deserve to be cured and others not. I am happy at the end that I was not selected, especially that I knew later that some people died while on trials from complications and from opportunistic disease. At the end, their families can't prove that they died out of the clinical trials, because they had AIDS, which is considered as a death sentence anyhow and any other infection can cause their death (Sama, Spring 2015).

The reflections of the three mothers give glimpses into their experiences during their encounter with the Complete Cure Device (called the CC device) or later termed as *Kofta* device by people and some media outlets, because Major. General Ibrahim Abdelatti (who was referred to as Dr. by the mothers) announced in the press conference that the device can extract the HIV virus from the body of the person and then can give the virus back as food in the form of *kofta* (meat skewer) to provide nutrition to the patient. Major General Abdelatti's attempt to simplify the explanation of the workings of the "Complete Cure Device" to the Egyptian public backfired as the national media quickly renamed it the "*Kofta* Device" or the "*Kofta* Joke"¹⁸.

Alia Abo Shahba, a journalist documented her one-year journey on the challenges of collecting information on treatment availability and hardships facing people living with HIV in Egypt. The daily *Roz Al Youssef* rejected her article for publication, on the grounds that this topic was not of interest to a larger reading public. It was only after two attempts that the online news website Masrawy published it on 12 August 2014. In her personal blog two days later, she wrote about the backstory of her experience of encountering General, Ibrahim Abdelatty and *Kofta* device.

"During my work on the investigative article about HIV and its treatment in Egypt, I encountered the "*Kofta*" General. It was in November 2013, almost three months before the press conference that was held on 23rd of February 2014 announcing the cure. General Abdelatty exploded from my following

¹⁸ http://www.huffingtonpost.com/2014/03/03/bassem-youssef-aids-hepatitis_n_4889382.html

questions: how come an army unit was established in governmental hospital like here (Homi'yat hospital in Abbaseya)? Why don't you share with people living with HIV that this device is still on experimenting phase, which can be successful, or not? The patient named X and XX had serious health conditions and their immunity systems were down after trying this "cure"? What is the nature of this "cure" exactly? If the patient named XXX has been cured totally, why would you not allow her to accompany me to do HIV blood tests in a well-known laboratory and examine if she was totally cured?

He was nervous, exploded in my face then he threatened to put me under military trial. Later, he changed his tone and said that he is presenting a global invention, which will shift Egypt position and place it first between countries. The interview was done between threats from other medical team surrounding him who were very violent as if they have no mercy in their hearts. At this point, I remembered the patient who cried heartily from their ill treatment so they all dismissed him. Later on, I focused on the pitfall of Ministry of Health and felt that this lie of the device will need another separate topic. Later on, they did the press conference in February 23 in 2014 and the truth was obvious to everyone without investigative article."¹⁹ (Alia Abo Shahba blog. 14 August 2014)

Conjuring ways of accumulating power

The Armed Forces in Egypt have a strong presence in many fields such as economy, medicine and politics, Khaled Fahmy used the metaphor of grey economy to describe these processes of absorption (Fahmy, 2012). Fahmy says "grey economy, in the sense that we know very little of them, they are not subject to any Parliamentary scrutiny, the Egyptian government auditing office has no control or knowledge of them"²⁰. For instance, Ex- officers receive managerial jobs in many institutions, have special access to military owned clubs and other real estate opportunities and control over 40% of the Egyptian economy through manufacturing and service companies in the country²¹. The announcement of the Complete Cure Device marks one of numerous moments since 2011 in which the Armed Forces presents itself explicitly as the guardian of the public good of the nation.

As one of my interlocutors put it "The abbreviated naming of the device as CC, was alarming for me and I was surprised because it is named like president Sisi. Then, I figured that we are being used for the coming presidential elections. All this made me rethink applying for the experiment and I didn't go". The attitudes of the

¹⁹ http://anaweelamargeran.blogspot.com/2014/08/blog-post_14.html

²⁰ <http://www.aljazeera.com/indepth/features/2012/02/2012215195912519142.html>

²¹ <http://circanews.com/news/explainer-egypts-military>

military and medical team who worked together in this process were highly alarming for both the people who experienced the trials whether as journalists or patients. In the words of another interlocutor: “it was a load, to think every time before answering the question, from where you got AIDS? They do not ask people with Hepatitis C for where you got it. I have no choice as I have to respond, because if I did not, they will judge me that I got the virus in shameful forbidden“ *haram*” way and not from my husband”.

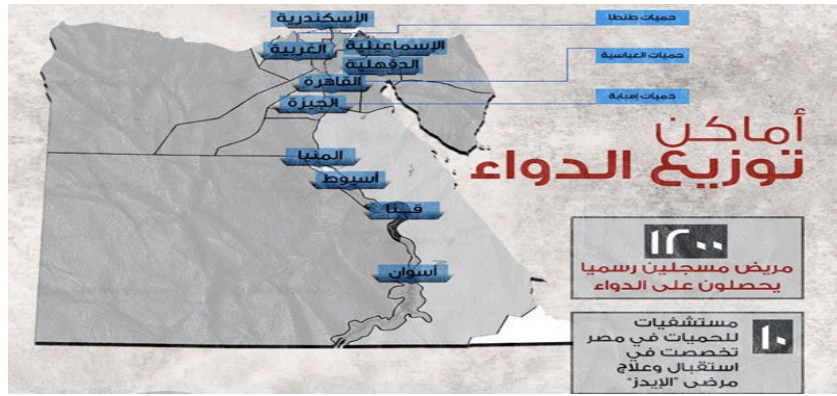
Chapter Three: Governing Care and treatment

Seeking Treatment

“When I knew that I have HIV from the doctor, I asked him to give me a prescription to go buy the medication from any pharmacy. He said it is not sold in pharmacies and it is very expensive. He advised me to go to the Ministry of Health to get the medication. At this moment, I didn’t have any information about HIV and the doctor talked about it saying AIDS and not HIV. I watched a movie once talking about Israeli girls who infected Egyptian guys with it and I knew it from there and was scared. However, with everyday living with it in my body, I am between two feelings. One of them is that it is a test from God like any other disease and many people are living with cancer or diabetes which comfort me for a while, then I have this other feeling pulling me every time I remember I can’t go buy medication from pharmacy or talk about my suffering with any one or even any doctor. You know, I am fluctuating between good and bad days like anyone” (Sama, Spring 2015).

“I sometimes forget that I have HIV. I only remember while taking the medication especially when my little daughter reminds me when I forget. It took me 9 years talking to God to give me patience and acceptance for my state. I remember the heavy visit to the hospital in Abbaseya where they distribute the medication every month and I was feeling shame when I went to get it every time. Now I don’t. I remember a nurse who looked at me in a way that was humiliating and was aggressive while I was receiving the medication. I called the doctor and had a big argument and reminded her how inhumane it is to do so. I don’t know from where I got this power, but I liked what I did. Did you know that I was as naïve as a blind cat before and wouldn’t stand or provoke any fight?” (Amal, Spring 2015).

There are ten distribution sites for the ARVs (HIV treatment) in Egypt located in the governmental fever (*homi ’yat*) hospitals that all people living with HIV/AIDS are required to go to on a monthly basis to receive their treatment. The three largest hospitals are Abbasiya and Imbaba in Cairo and Tanta in the Delta and these are the preferred sites for most people as they guarantee a certain degree of anonymity in contrast to smaller provincial hospitals. The Global Fund provides the resources for the medication through its funding of the National AIDS program.



The number of people living with HIV over 15 years old in Egypt is estimated as 7200 with range between 4400 and 12000 with estimated prevalence rate of 0.013% among the 84 million population of Egypt (United Nations Joint program of HIV/AIDS Annual Global Gap Report 2014). The number shared by the National AIDS program by the end of 2014 was 4631 people. Out of these, 1715 were registered to receive HIV treatment. This number (11000 to 12000) of infected people has been used for 10 years as an estimate. I first encountered this number in 2005 when I volunteered in a UNAIDS awareness session as a medical student.

Medical encounters and diseased attitudes

The stigma that people living with HIV encounter from health service providers is remarkable. It pushes them not to disclose their status sometimes to healthcare staff to avoid refusal or mistreatment. A social worker that I interviewed for this thesis, and who provides psychosocial support to recently diagnosed people with HIV observed that “the medication is provided and the attitudes of people disbursing the medication are improving. But this is only in big hospitals in Cairo and Giza. I come from Ismailia governorate, and I have a friend working in the hospital as pharmacist, and she disburses the medication to people living with HIV on Wednesdays. She once mentioned to me that she feels pity for the HIV people because everyone knows their status when they come for the medication and suffer from judgmental looks from staff and patients. She wished that they would go on Friday for example to get the medication not Wednesday”.

There has been some progress in the training of staff at the three large hospitals on how to treat people living with HIV and AIDS. Hence, many people travel great distances to ensure decent treatment and anonymity away from their

communities. Maha recalls the complex challenges in getting access to medication before her child was born:

It was late 2010 when I went to obtain the HIV treatment for my unborn baby and I found out that it was getting expired in two months before the birthdate of my child. I contacted the NAP and there was a problem that the treatment imported was being investigated in the Egyptian Customs and it took a long time in bureaucratic measures to get the treatment out of the port. I was panicking and kept praying that the new patch would arrive before the birth of my child because I couldn't get the medication. I was supposed to give birth by caesarian section late January 2011 to minimize the risk of infecting my child. My gynecologist was not reachable. I had the support of my friends and husband who are living with HIV as well to reach out for people in civil society to find a doctor who would help me give birth and know my status. We couldn't find anyone. At last, a doctor in Alexandria who works in HIV prevention program in an NGO volunteered to give me 2000 Egyptian pounds to do the cesarean section, God bless him, I pray for him every time I see my child. The gynecologist who did the operation didn't know my status. I couldn't share with him because he would have refused to operate and I would have given birth normally which would harm my child. I kept telling myself, he should sterilize the equipment after me and I told him so. I gave birth on 3rd of February 2011. The country was boiling back then in 25 January revolution and I remember watching the camel battle on 2nd of February on TV before giving birth. I would never forget the worries and prayers to let everything pass peacefully and protect my child and those young people I saw in the square. My child came out HIV negative thanks God, the powder milk was secured by UNAIDS because I should not breastfeed him" (Maha, Spring 2015)

Maha was facing the dilemma of trying to find a doctor to facilitate her delivery, while at the same time meetings were held to develop the National AIDS strategy for Egypt from 2012-2016 in January and February 2011 (National AIDS Program, Concept note, June 2015). The process of developing the National HIV strategy usually has the most important stakeholders gathered together to draft the HIV plan for care, support and treatment. Maha knew about this from a friend who was invited to the meetings as a person living with HIV. She said: "They all gathered together in meetings and couldn't help me to find a doctor who would be willing to deliver my baby because I have HIV, I felt bitter and sad" (Maha, Spring 2015).

A person living with HIV has to navigate difficulties of living with HIV in the Egyptian bureaucratic hurdles. The journey of the HIV treatment to arrive to the people takes time due to bureaucratic measures starting in the customs at the port.

UNAIDS country coordinator Dr. Ahmed Khamis mentioned that the HIV treatment is stored at Ministry of Health and there is a delay in importing newly manufactured treatment because the Ministry waits until they disperse most of their stored medication. This adds to the bureaucratic measures at customs, which results in the late arrival of the treatment to the hands of the people who need it, as it usually takes up to 6 months and sometimes a year, from the time of ordering it by the Ministry of Health from abroad until its arrival.²² However, in an investigative article published in August 2014 by Alia Abo Shahba in which she interviewed Dr. Walid Kamal, the assigned director of National AIDS Program since December 2013, he highlighted that the Ministry orders the medication within enough suitable time and it does not neglect or delay in ordering, but sometimes some disturbances happen at the customs. Alia's article about the journey of the treatment was detailed and was an example of informative and truthful efforts done to secure accurate and transparent information to the public. I discussed some of the information in the article with my interlocutors especially the mothers and they confirmed the information presented in it. Samira, one of the mothers said:

“I got really sick and had to visit Abbasiya fever hospital 4 years ago. The attitude of the nurses varied to a high degree. Some of them made me feel worthless and I was in a state that I could not argue or explain how I contracted the virus, others were kind but I felt out of pity. It takes one person to ruin my emotional state and make me feel agony besides my deep worries that I might die here and never see my children again. Doctors come and check me and then they would go, but the nurses were all around and talk. Nurses don't know a lot about HIV so at least I wanted them to keep their talks to themselves.”

Maha reflected also on this ” I know some people who are having terrible stories getting medication and treatment. I see the end result that sometimes, some of us, are not able to get our medication on time. Do the people in customs know how important

²²http://www.masrawy.com/News/News_Reports/details/2014/8/12/319061/%D8%A7%D9%84%D8%AA%D8%B1%D9%8A%D8%A7%D9%82-%D8%A7%D9%84%D9%82%D8%A7%D8%AA%D9%84-%D9%85%D8%AA%D8%B9%D8%A7%D9%8A%D8%B4%D9%88%D9%86-%D9%85%D8%B9-%D8%A7%D9%84%D8%A5%D9%8A%D8%AF%D8%B2-%D9%8A%D9%88%D8%A7%D8%AC%D9%87%D9%88%D9%86-%D8%A7%D9%86%D9%87%D9%8A%D8%A7%D8%B1-%D8%A7%D9%84%D9%85%D9%86%D8%A7%D8%B9%D8%A9-%D9%88%D8%A7%D9%84%D9%88%D9%81%D8%A7%D8%A9 and in a Skype interview with me on 26th of May 2015

it is to get our medication at the same time every day or we would be beaten by the virus? Can they imagine themselves in our places?”

Amal expressed her worries that she might need to change her medication because she learnt from the NGO where she attends the support group about drug resistance. She said:

“I knew that I need to change the medication and take another type as the virus would resist the medication in the future. To do the testing to check if I developed drug resistance or not is very expensive and not available at the Ministry of health and takes time. When you go to a doctor for flu and take antibiotics, you change them after a while for effectiveness. I am afraid that I will get one day to a point of taking my medication with all the worries that it is not effective anymore and I might get sick anytime, to live with this thought is not easy, but I immediately say “God will take care of me for the sake of my kids” and I throw the thought away to continue my day.”

Veena Das has mentioned the “complex relations between the experience and representation in illness narratives” in her article “How the body speaks: Illness and life world among urban poor,” Usually scholars are caught between analyzing the political economy of the illness narrative or its meaning which creates a binary opposition between culture and political economy (Das, 2007). She narrated the illness experiences in an attempt to understand how people are living their lives in the urban poor neighborhood of India (Das, 2007). Das stated it in her article, while talking about TB strategies, that strategies and decision makers who draft those strategies to control epidemics have a sublime tendency to blame the patients of being culturally “inadequate” to follow the treatment regimen “strategy has led to practices built on the assumption that patients who do not recover are noncompliant whereas treatments are always efficacious” (Das, 2007, p. 87).

In Alia Abu Shahba’s article, the point of being culturally or morally inadequate to be treated was addressed when she did an interview with the former Minister of Health, Dr. Maha Rabat. Alia stated in the article “when I asked Dr. Maha El Rabat about the irregularity of dispersing HIV medication to the patients in the outlets assigned by Ministry of Health in Fever Hospitals especially in Tanta Fever Hospital, which is in the Delta region, she said she will investigate and send people to check the availability of the medication. Dr. Maha Rabat insisted that the medication

is available in the stores of the hospital and is regularly dispersed on monthly basis, the problem according to her was the behavior of the patients, who go more than once per month to get the medication out of their insecurity that the medication would vanish and run out. Dr. Maha reviewed the investigation that I worked on and after she reviewed the report coming from Tanta Hospital, she confirmed that there is a problem there. However, she stated that the patients are “over sensitive” about their status which leads them to over react and over complain about their situation”²³. It is a well-known medical fact that people living with HIV have to take their medication on a daily basis and at the exact same time to protect them from other opportunistic infection and control the virus from destroying their immune system. The interviewed people who are living with HIV expressed their deep concerns and sense of insecurity regarding the thoughts of not having the medications package in front of them every day.

Transnational governance for HIV treatment and care

The funding for the medication comes from the Global Fund,²⁴ which is the largest financier for Anti HIV/AIDS, Tuberculosis and Malaria programs worldwide. It provides grants to Egypt since April 2008. Up to date a total of 30.59 million USD was granted to Egypt’s Ministry of Health in HIV/AIDS and Tuberculosis programs as principle recipients of the grants. The table below from Global Fund website.

Component	Signed	Committed	Disbursed
HIV/AIDS	US\$12,155,723	US\$9,719,337	US\$9,319,337
TUBERCULOSIS	US\$18,440,173	US\$12,977,478	US\$12,936,295
TOTAL	US\$30,595,896	US\$22,696,814	

Investments in Egypt -Global Fund site 1

²³http://www.masrawy.com/News/News_Reports/details/2014/8/12/319061/%D8%A7%D9%84%D8%AA%D8%B1%D9%8A%D8%A7%D9%82-%D8%A7%D9%84%D9%82%D8%A7%D8%AA%D9%84-%D9%85%D8%AA%D8%B9%D8%A7%D9%8A%D8%B4%D9%88%D9%86-%D9%85

Focusing on HIV/AIDS related programming, the following mechanism should be in place to receive a grant from the Global Fund. The country needs to have a Country Coordinating Mechanism (CCM) that includes representatives from both public and private sectors (governments, multilateral or bilateral agencies like UN agencies, NGOs, private businesses, academic institutions and people living with the disease). The CCM drafts the proposal for the grant from Global Fund and elects a principle recipient who receives and monitors the implementation of the activities under the grant (Global Fund official website). The CCM monitors the activities and takes collective decisions through meetings to follow up on the process. CCM develops the National Strategic plan for combating the disease and provides the needed care and support. There are also “Local Fund Agents” who are described in the Global Fund website as “The Global Fund does not have a presence in country; all staff are based at the Secretariat in Geneva, Switzerland. Instead we rely on independent organizations in each country known as “Local Fund Agents” to serve as our eyes and ears on the ground” (Global Fund official website).

Egypt has been following the procedures and formed the CCM to be able to secure the grant. One way or another, this obligatory measure to receive the fund has helped in gathering many people on the same table to discuss and talk and work together to guarantee the Fund. How the Fund is managed is another question that we will come to figure out in the following lines. In case of Egypt, the CCM was formed of the National AIDS program as a principle recipient for the NGOs working in prevention and support programs on HIV/AIDS, UNAIDS and UNICEF and people living with HIV. As a result, Global Fund website indicates that currently 1600 persons living with HIV are receiving their medication up to 2015. To link this information to the worries of Amal, the mother that is concerned that she might develop drug resistance and her medications that she is receiving would turn to be no more effective, I find this number not sufficient to represent how many needed to change the course of their medication or who are in urgent need to change the medication regimen to respond to the resistance of the drug. Moreover, it does not indicate who is taking the drug continuously and adheres to the treatment regimen. The medication would be available and 1600 or more are registered, however, how effective is that, would be the question that need to be answered by CCM in Egypt and to be carefully monitored by Global Fund officials.

The misconduct

In a report published in September 2015 by the Office of Inspector General in the Global Fund, misconduct in expenditure by the managing team in the Ministry of Health, National AIDS program unit was revealed in round 6 of the Global Fund grant. As written in the report “The Secretariat tasked the new Local Fund Agent to undertake a review of transactions for quarters 19 and 20 (October 2012 to March 2013) of Round 6 of the HIV grant” (Global Fund Office of Inspector General , 2015). The investigation report quoted above discovered “irregularities in expenditures” totaling 668,877 USD in the mentioned period. The Global Fund questioned the Local Fund agent quality and independence of information on the spent money in late 2012. The Local Fund agent resigned and a new one was assigned. The Global Fund asked the new assigned Local Fund for 2015 grant to review the expenditure of Ministry of Health, NAP program with an investigation team from the Global Fund Secretariat. They found the following “The Local Fund Agent’s review highlighted irregularities in expenditures relating to: hotel accommodation; hiring of vehicles and halls; catering; t-shirts; stationery; brochures; banners; office supplies; silver medals; car repairs; and miscellaneous expenses”. As the report indicated, hotel bills were made to non-existing hotels and transportation contracts were signed with ghostly companies. Moreover, procurement of T-shirts and brochures required for awareness programs were secured through a specific vendor with clear misconduct of Egyptian Law and Global Fund procurement procedures. The total of 668,877 USD was misused and Global Fund is holding the National AIDS program accountable to return them back to the Fund.

The Global Fund provided a new grant to Egypt starting 31 of August 2015. The decision of the Global Fund was to cut the money for the training component for health professionals under the HIV grant, as the scope of the grant is critical lifesaving activities like medications or testing equipment .The figure, as indicated in the table above, is 9.72 million USD. In the report, it was indicated that the Former director of National AIDS Program managing the previous grant has to be changed. The new director Dr. Walid Kamal was assigned to manage NAP in December 2013, which is after the previous period from October 2012 to March 2013 that indicates the misconduct. All of my interlocutors expressed their happiness of the change of the NAP director. Amal said “Dr. Walid has been in the NAP since a long time and his

attitude and kindness were manifested, unlike the previous one.” Maha, who had a problem with a medical doctor who treated her badly and caused sever complications to her gall bladder operation said:

When I presented my problem of where to find a surgeon to do the gall bladder operation to Dr. Walid Kamal, he recommended a surgeon who was trained on HIV and AIDS information and was involved in the workshops and meetings on HIV. I went to that doctor with my sister. We waited for almost 10 hours past my operation time to enter the operation theatre. He made me wait until the end; I was hungry and didn't eat prior to those 10 hours. He operated and I had serious complications after as he forgot cotton pieces in my abdomen. The pain was intolerable and every time I go to him, he said that I would improve. Later on he said, I didn't operate on you and kicked me out. I went to Dr. Walid and told him what happened, Dr. Walid was very supportive and I filled a lawsuit against this doctor. Now, I am managing the complications of the gall bladder operation with another doctor. He is a very merciful and good doctor that I went to by myself on suggestions from relatives. I went to him twice and every time I think, should I tell him that I have HIV? Would he change and kick me out if he knew? I don't need another operation now, so I don't need to tell him that I am living with HIV. (Maha, Spring 2015)

With jeopardizing the previous grant and the proven misconduct, the much-needed training of doctors and nurses was cut as they were out of funds. Clearly, previous training approaches were not proven efficient according to the stories of the medical encounters described by the mothers. Yet, the question remains, how proper care can be provided without enough support from the health sector personnel who are in close contact with the people living with HIV? Simple or major health sickness and operations for them and the struggle to find a doctor to deal with them is expressed as major life worries and challenges by all of my interlocutors. Dr. Ahmed Khamis, UNAIDS country coordinator said

We are trying to develop a network of health personnel who would work with people living with HIV. In all specialties we have names but they need more trainings and monitoring and to expand the network. We have been doing awareness raising work with medical students in medical schools trying to tackle this issue from the start and we will continue working on that along with securing a referral list of health personals. We are fully aware of other infections called opportunistic infections that a person living with HIV can contract, hence it is not only securing medications but few are working towards full medical care system. (Dr. Ahmed Khamis, Skype interview 26 May 2015).

I discussed the change in NAP management with Dr. Ahmed Khamis and he stated:

The challenges that NAP faces are ranging from low number of staff and the low capacity of their existing staff. The new management of NAP has changed the response of HIV into a more transparent one. Now, NAP management is willing to improve and welcoming other international entities, NGOs and people living with HIV. Dr. Walid Kamal is a great person and he works on a personal basis as well as a professional one to support people living with HIV. Previous NAP management was the opposite of this. However, Dr. Walid doesn't work alone, he needs support in forms of well-qualified staff working with him in NAP. We are now, in May 2015, finalizing the National HIV Strategic plan for 2015- 2020 with budgeted operational plan for 2015- 2018. There is a concept note that will be sent to the Global Fund for the grant application. NAP now has changed, they ask for help and they are aware of their need to develop their capacities. (Dr. Ahmed Khamis, Skype interview 26 May 2015).

Between the written and the enacted: analyzing selected national documents on HIV and AIDS

Indeed, the concept note that was developed in June 2015 has highlighted the main drawbacks in previous strategies and activities related to HIV and AIDS in Egypt. This concept note was mandatory to explain the situation in a holistic and transparent way to the Global Fund to be able to obtain the grant for the coming years and the grant was secured as highlighted above on 31 August 2015. Below, I offer an analysis of the main points of the concept note and reflect on the programming approach targeting HIV and AIDS.

The concept note was drafted on 21 of June 2015 to be presented to the Global Fund to secure the grant. The process of drafting the note included a series of consultation meetings with representatives of non-governmental entities, UN entities, and people living with HIV, along with National AIDS Program staff and the elected Country Coordinating Mechanism body for the Global Fund in Egypt. The concept note included initially a training component, which was not approved by the Global Fund Focal Point for the Middle East North Africa region who stressed on funding lifesaving activities only in light of the misconduct, which was proven in Global Fund investigation report in September 2015.

The committee that drafted the concept note had to revise the note and activities were deleted in the final document such as training judges on HIV and AIDS legal needs, reducing the number of medical doctors who will be trained on HIV and AIDS and focusing only on fever hospitals' doctors who provide medical support for people living with HIV, canceling stigma and discrimination campaigns and training manual. In addition to reducing the funding for outreach activities among commercial sex workers and increasing the funding for outreach activities among men having sex with men and people who inject drugs in Cairo, Alexandria, Gharbeya governorates and scaling up to more governorates with establishing a center providing comprehensive care and support for men having sex with men and people who inject drugs in Alexandria.

The concept note stated the fact that there was limited progress in achieving the outcomes of the previous National HIV Strategy for 2012-2016. It emphasized the main pillars for the new strategy of 2015-2020 with budgeted operational plan for 3 years. Those main pillars were identified through a series of consultation meetings to define the gaps in programming for HIV and AIDS in March and April 2015.

As stated in the documents, it is challenging to women who work in commercial sex or women who are using drugs. One of the social workers said, "Sex work as a category of labor is not identified by itself; usually the women work in other working class jobs and do take money for sexual acts. It is challenging to reach out for them due to our conservative nature and taboo. However, they need medical and legal care and follow up, especially since they suffer from violence with their clients and cannot negotiate condom use with a client. It is the client's decision. Priorities set in new strategic plan would affect the funds allocated to address their needs" (Personal interview, spring 2015)

National HIV Strategic Plan 2012-2016

I will start with a brief history about the formation of National AIDS Program (NAP) in Egypt. From UNAIDS official website, the profile of Egypt was as follows: "In 1987, the National AIDS Programme (NAP) was established by a ministerial decree in order to lead the National response against HIV and AIDS. Since then, the NAP has implemented three 5-year National Strategic Plans (NSP), 1995-2000 and

2001-2005 and NSP (2007-2011). The NSP is developed with inputs from several key government sectors, namely the Ministry of Interior, the Ministry of Information and the Ministry of Youth, in addition to civil society (The Egypt Business Coalition on HIV, the Egyptian NGO Network against AIDS, people living with HIV and other national and international agencies). The National Strategic Plan (NSP) on HIV and AIDS is the most comprehensive framework addressing the National response to HIV and AIDS in Egypt. The NSP comprises all national priorities on HIV and remedial actions.

I reviewed the main national documents that represent the national response towards HIV and AIDS such as the strategy of National AIDS Program for 5 years (2012-2016) with overarching goal to “stabilize the epidemic growth, prevent new infections within the most at risk population and improve health outcomes for PLHIV”. The other document was the official narrative report on the national response towards HIV and AIDS in 2012. The Egyptian national response report was written according to the guidelines of the Global AIDS Response Progress Reporting (GARPR) 2012. The global AIDS response progress reporting guidelines were developed by WHO, UNICEF and UNAIDS and disseminated between countries to publish a global report yearly to highlight the global progress in response towards AIDS worldwide. The data in the Egyptian national response report was largely collected by a taskforce comprising of technical officers from both the National AIDS Program (NAP) and UNAIDS country office Egypt. As stated in the report, “consultations with several governmental officers, Civil Society Organizations and the UN system took place during data collection” (Global AIDS Response Progress Reporting (GARPR) 2012).

The examination and analysis process of the two documents is important to understand how the topic of HIV and AIDS is being addressed at the policy level with particular ordering of the national priorities and public health strategies. The two documents were drafted by the National AIDS Program affiliated to the Ministry of Health and international agencies such as UNAIDS, which is the lead multilateral organization coordinating the global response to HIV/AIDS. Hence, the official documents represent the envisioned path that should be followed to address HIV and AIDS by both entities at the national level. However, the mothers that I interviewed knew very little about those documents, although some of them do outreach work and

help other newly diagnosed people with HIV. One of their main concerns is the scarce focus on mothers and children living with HIV. Magda, one of the mothers living with HIV said “I find it difficult to find doctors who would accept doing check up on me or my child knowing that we both live with HIV. I am not involved in the meetings related to HIV conducted by some NGOs, however I get sometimes the names of the doctors from a friend living with HIV who attends events of those NGOs. Would it be possible to go to any doctor and not to think of all the hassle and the embarrassment that I feel when my child or I get sick?” Samira said, “the words on the documents seem solid, lifeless. The burden of living with HIV is one of many burdens I carry, mostly the need to learn a craft or find a job. I can get sick anytime and small microbe can affect me more than any other person. I want to see this included in the documents of the government like the one you told us about now.”

Medical care is the responsibility of the NAP and is conducted through free provision of Anti Retro Viral (ARVs) for people who need it, follow-up and counseling and treatment of opportunistic infections as stated in the documents. A home-based care program for PLHIV is in place in Alexandria and Cairo providing home visits to HIV affected people and trainings for PLHIV and their families raising awareness and clarifying misconceptions about the disease. In addition, as part of the home based care initiative, the group has been working with health care providers to improve treatment and care for PLHIV (UNAIDS, Global AIDS Response Progress Reporting (GARPR), 2012).

The UN, the Global Fund, and other donors support civil society organizations. They implement peer education programs on HIV for vulnerable groups (street children, refugees and prisoners) and several outreach and prevention programs for the most at risk populations (people who inject drugs, men having sex with men and female sex workers).

While drafting the NSP for 2012 in early 2011, the total number of people living with HIV receiving ARVs as of 2011 was 760, including 701 adults, 40 children and 19 refugees (UNAIDS, Global AIDS Response Progress Reporting (GARPR), 2012). Additionally, “The NAP has activated a process of decentralization of ARVs distribution system as a result PLHIV are now able to access ARVs through 6 distribution points located in 5 governorates (Cairo, Giza, Gharbia, Alexandria and Menia), while initially ARVs were available only in Cairo. Although ARV drugs are

available for patients in Egypt, the selection of ARVs distributed is still limited and especially for those who develop resistance”ii.

The 2015 developed concept note for new grant from the Global Fund addressed the progress of the NSP for 2012-2016 and its implemented activities. The following paragraphs were paraphrased from the concept note which confirmed that there was no national monitoring or evaluation system to track the implementation of activities; information was collected neither on systematic nor properly documented manners and there was no clear population estimates published to respond to the percentage and numbers assessing the success of any outcome aspired from NSP. The objectives focused on prevention of HIV prevalence from exceeding 5% between “key populations”, a term widely used to describe three groups (men who have sex with men, sex workers and people who inject drugs). The other objective was to prevent mother to child transmission of HIV through covering 60% of pregnant women in 50 clinics. The concept note was clear and transparent that all the outcomes of NSP for that particular period “were not measured and not achieved” (National AIDS Program, Concept note, June 2015). The outcomes under those objectives aspire, for example, to reduce stigma between health care providers in 4 big fever hospitals that manage the cases of people living with HIV, providing care and treatment and support to 80% of people who need it, the prevention of the increase of the prevalence of HIV among certain groups through prevention and awareness activities, providing care to 60% of pregnant women including HIV treatment for them and their newborns, emphasizing provider initiated testing and counseling and harm reduction activities that provide clean syringes and condoms to people who inject drugs and implement income generating projects.

The agreed upon strategy and the need to define percentage and numbers of people to be “targeted” contributes only and solely to a “successful” document. In development language, the mention of quantitative percentage is a must to assess an “achievable” outcome. That was the case with this strategy and other documents as well. Yet, the gap remains between the numbers mentioned and the realities of the people that I had interviews with. The collective numbers can give an idea of working for a “common and public” good. Yet, parallel to that drafted strategy, the lives of the people who are to be served were dynamic and evolving along streams of political, personal, health and security demands. Moreover, the estimated numbers in the

strategy that measure “success” did not have a solid base of population studies, availability of data and transparent research. Yet, it was placed as a national strategy for almost 5 years.

National HIV Strategic Plan 2015-2020

The application process of the Global Fund grant and the unachievable outcomes of previous NSP required new process to develop HIV National Strategy form 2015-2020 (National AIDS Program, Concept note, June 2015). The process of this new national strategy sounds promising. From the information provided by Dr. Ahmed Khamis and the developed concept note, it is tangible that the National AIDS program is willing to develop the capacity and skills of people working in it and improves the management of the program. Although there is no national overall health strategy approved to this date and the HIV national strategy will be reviewed and approved by the Minister of Health to make sure it contributes to the draft of an overall national health strategy. As mentioned in the concept note “A multi-stakeholder consultation process was undertaken to develop a Programme Gap Analysis in April of 2015 and this process segued into one for the Strategic Framework and Cost Operational Plan. Stakeholders included governmental and non-governmental institutions and development partners. People living with HIV and members of the key populations of people who inject drugs and men who have sex with men, were all full participants in the process. The National Strategic Framework 2015 to 2020 is a concise fifteen page document with the four pillars of 1) prevention, 2) testing, care, support & treatment, 3) enabling environment, and 4) management, coordination & knowledge generation. There are no overall goals and objectives for the strategic framework” (National AIDS Program, Concept note, June 2015).

The drafting of the new strategy was different and more realistic in terms of the language used. For example, the percentage and targeted “quantitative” measures were linked to annual specific numbers with acknowledgment of poor statistical data as dominators. The focus is still on “key population” in addition to prisoners, children living in streets and refugees. The new strategy encouraged provider-initiated testing along with voluntary testing. In addition to that, it adopted harm reduction approach to provide clean syringes acknowledging for the first time the future willingness to refer for opiate substitution therapy for Heroin injecting drug users. However, focused

on specific governorates such as Cairo, Alexandria, Minya and Luxor in addition to Garbeia governorate. Dr. Ahmed responded to that question on why focusing on only those governorates arguing:

Strategic direction should be cost effective and maximize the benefits. If we have a grant that it is decreasing with low funding opportunities, then we need to cover outreach and key population. The biggest numbers are in Cairo and Alexandria and we are focusing on 5 governorates that attract more people from other governorates. UNAIDS is doing outreach projects in Alexandria and Tanta with aspired outcomes to cover 80% of key population there after 5 years. Decentralization of viral load testing is ongoing, so they don't need to come every 6 months to Ministry of health for measuring the progress/load of the virus in the blood. Along with NAP, we are looking forward to get a device that will assess the resistance developed from the HIV treatment in the coming period. (Dr. Ahmed Khamis, Skype interview on 26th May 2015)

Magda, one of the mothers, said:

It took me one year to enter to treatment regimen because of my hesitation to go to the Ministry and get registered. I was afraid that my name would be known, people would know and the shame of living with HIV will follow me to my neighborhood. I knew that I am HIV from a private laboratory and there was no counseling and the person there told me to go to Ministry of Health and gave me the address. After one year, skin patches started to show on my arm and I had a sore throat most of the time. I lost weight too although I was trying to eat well. At this point I went to the ministry and I was assured that I will be fine after getting the treatment. (Magda, spring 2015)

Magda's talk indicates that not everyone is willing to go through the process of getting registered for treatment and care from the ministry after knowing about their status, an issue that would affect the lives of many. Mostly, there is no trust that there will be confidentiality or efficiency of the treatment or better attitude of people in health care system. This problematic was highlighted in the new HIV strategy 2015-2020. The document states the following "The strategic objectives for Area 2 on care, support, and treatment are to increase the number of people living with HIV who enter care and to increase the number of people living with HIV who are retained in care. With respect to targets, for the purposes of the strategic plan it was estimated that there were 7,200 people living with HIV so 90% of them or 6,480 would learn that they have HIV, 90% of them or 5,832 would have initiated antiretroviral treatment, and 90% of them or 5,249 would achieve viral suppression" (National AIDS Program, Concept note, June 2015)

Concluding remarks

Moral questions are contested in public health debates. For example, there is a notion which is promoted by health economists called Quality-Adjusted Life Year (QALY) which was invented by two health economists in 1956: Christopher Cundell and Carlos McCartney, and described as an equation that measures the disease burden to help policy makers in drafting health strategies and allocate budget for medical interventions (Schlander, 2010). This equation depends on measuring the quality and the number of years lived by a person living with a certain health condition and what is the cost benefit of providing certain medical intervention to treat that person or to contribute to increasing the life expectancy versus the quality of the life lived. That means in chronic diseases in which the quality of lives will not be totally cured by the medical intervention, the life expectancy years are calculated in case of providing the needed medical help and hence the political decision would be made if that chronic health status would be worth supporting or not (Schlander, 2010). Based on what we can call a life as a “quality life” or “not “ and based on what decisions are made about allocating budget for terminally ill people? Or is it worth treating an old person? (Schlander, 2010)

The bio-political aspect of HIV was tailored through the different strategies and interventions that were designed by communities to control the spread of the pandemic. Heads of international and political agencies with developmental agendas such as the United Nations emphasized the need to have strong political will and involvement of the decision making bodies to control the virus. However, what is the impact of the language and policies used in HIV and AIDS response over different populations? As Veena Das talking about TB strategies that usually blame the patients of being culturally “inadequate” to follow the treatment regimen “strategy has led to practices built on the assumption that patients who do not recover are noncompliant whereas treatments are always efficacious” (Das, 2007, p. 87). For instance, the former Egyptian Health Minister described the people in need of medication as “non compliant” or “over sensitive”. Additionally, if the political will is there to curb the epidemic, the question is how the best interest of the people is being calculated and based on what? For example in the coming chapter, I address the issue of harm reduction and the approval of future strategy beside emphasizing current work to distribute clean syringes and condoms in addition to opiate substitution treatment. It

was a technique frequently and passionately advocated for to prevent HIV and AIDS, however, would that decrease the stigma around HIV and AIDS? The person who injects drugs for example would obtain a clean syringe, however, how would he be treated if he were arrested by police officers? There are documented incidences of the surveillance and multiple arrests of gay people by Egyptian police were aforementioned in the research, hence, how would this affect the agency of the person to go seek a clean syringe or a new condom? Ending the chapters with those questions to put this perspective on the table to contemplate what we are wishing for and how it is being implemented rather than negatively criticizing its presence as a technique.

Chapter Four: Technologies of Harm Reduction

Technologies here refer to the ways in which harm reduction is conceptualized, constituted and sustained. The term is inspired by Foucault's concept of "Technologies of the self". In this context, I opt to look at harm reduction through two perspectives. First, the concept of harm reduction when addressed in the field of HIV and AIDS translates automatically to providing clean syringes or new condoms for people who inject drugs or for people who are having sexual intercourses to be "safe" from contracting HIV. Hence, this is one of the perspectives that I am talking about later in this chapter. The other perspective is looking at harm reduction as in other prevention methods adopted by community and international organizations working in HIV and AIDS as well as testing services for HIV to know the diagnosis as well as follow up on the development of the virus in the body.,

Testing for HIV

Every time I go there, for the routine CD4 testing I come back home more depressed. Why? Because of the people around there, the small place is crowded with people and we all look anxious, depressed and I sometimes we are faced that the testing equipment is broke. I am lucky because I live in Cairo. Many people I see on the testing site in the Ministry of Health travel from Upper Egypt or Delta region and come here. It is just so depressing there and many times I skip to know my CD4 or viral load because I think about the load that I carry after leaving the Ministry. But I have to go back in the end. (Samira , Spring 2015)

I had an experience encountering testing for HIV. In 2006, I went to do an HIV testing in Voluntary Counseling and testing center (VCT) located in the Ministry of Health in Sheikh Rihan Street. I remember the week before this visit when I was thinking that if I am talking about eliminating stigma and discrimination around HIV and the process of testing for the virus, I should try that myself. I took the decision and woke up early in the morning and travelled from my home city "Mansoura" to Cairo to do the testing. I arrived there and asked at the entrance about the National AIDS Program department and then when I arrived to that section I asked about where to do HIV testing. I remember carrying my back bag and holding its arms with my hands with straight back posture but my hand were sweating and I made an effort to maintain a steady status. The adrenaline rush was intense. I remember the look on the face of the person who should do the rapid test and he did ask me about my name while looking at my fingers looking for a ring! Expecting or wishing that I would be

married somehow! Anyhow, I refused to give him my national Identification Card and did give him a fake name saying that I was referred to him by a well-known doctor who is working in the field of HIV as an activist in Alexandria. He did not do counseling. May be he assumed that since I am in contact with that doctor, so I would know how HIV is being transmitted. He did the test and gave me a code to come next week to get the results. As I used to say that the rapid testing of HIV would give you the results in maximum 10 to 20 minutes, I was surprised that he is asking me to come after a week! I walked out of the building feeling accomplished yet totally drained and fragile. The person who performed the rapid testing did not tell me any direct bad or aggressive words. Yet, it all showed in his eyes and gestures. He is looking for more details. I found that intimidating and not comforting at all. Additionally, there was neither counseling provided nor confidentiality that he should be ensuring when he asked for my name and ID. At the end, I told myself that I was experimenting! I was trying to put myself in the shoes of a person who doubts that he might have contracted HIV somehow! But the truth is, I had the energy and realization that I do not have the virus and that contributed to my self-esteem and confidence while setting in front of the person who was performing the rapid test. However, how about going for testing with loads of doubt and skepticism? Is he going to get his/her results after one week? How does the anticipation for the results and the eagerness to know or not to know the HIV status affect the follow up on laboratory tests and its waiting period was one of the questions. However, while I was conducting the fieldwork for this research, I learnt from different interlocutors that rapid tests results are delivered now on the spot same day.

In the National AIDS Strategy documents, blood testing for HIV was emphasized as the only way to know about the presence of the virus inside the body. Due to the lack of information and the presence of misconceptions about HIV that led to HIV associated stigma and discrimination, there are estimates that only one person in 5 living with HIV who knows about their seropositive status (UNAIDS website). It is important to highlight that the prevalence of HIV in the country appears to remain below 0.01%. However, a population based survey was never conducted in Egypt.” (UNAIDS, Global AIDS Response Progress Reporting (GARPR), 2012). There is an increase in the number of detected HIV positive cases. For example, the declared number of HIV cumulative cases at the end of 2010 were 4,313 and 468 new cases were detected in 2011 only (NAP data 2010-11).

International guidelines about testing published in 2004 by UNAIDS and WHO stated clearly that the process of testing for HIV should be based on informed consent, counseling and confidentiality. Those three guidelines are the main pillars for a process of testing that ensures the rights of the person living with HIV. Informed consent also means that the person should have information about the consequences of testing especially in prevention efforts and early detection of the virus through counseling process before and after the testing. The process of counseling should inform the person about the follow-up in case of being diagnosed with the virus and the importance of notifying other people who might be at risk. The right to refuse doing the test is important to be exercised according to the decision of the person. That is what is called voluntary testing, which means that the person go by himself to ask for information and to perform the testing if they desire in voluntary testing and counseling centers.

“The service of voluntary counseling and testing VCT was developed in Egypt since 2004. Egypt has 23 governmental VCT units providing voluntary counseling and testing services (14 fixed and 9 mobile) which are operational in 17 governorates. In addition, 5 NGOs (Caritas, Refugee Egypt, Waay, Hayat and Be-Frienders) provide VCT services. Two models of VCT units are available; stand-alone (fixed) and mobile units. All service units are supposed to provide pre-test counseling sessions through trained counselors, HIV testing with complete anonymity, secured level of confidentiality and well established referral network. In 2010 a reported number of 9,554 visitors accessed VCT services while in 2011 the total reported number is 6,489. MARPs visits accounted for 15.27% and 22.6% of the total visits in 2010 and 2011 respectively. Women utilization of VCT services is still low and it is reported at 18.5% (2010) and 16.18% (2011) of all VCCT visitors (NAP data 2011). In addition, the 5 NGOs (Caritas, Refugee Egypt, Waay, Hayat and Be-Frienders) provided VCT services for 1869 MARPs in 2010.” (UNAIDS, Global AIDS Response Progress Reporting (GARPR), 2012)

Dr. Ahmed Khamis commented on VCT number saying:

VCT centers that run through NAP were supported by UNFPA. UNFPA stopped funding the VCT with no exit strategy. The support of UNPFA was cut because of the difference in points of view and the culture of management in MoH and UNFPA. VCT centers are running in minimal capacity of staff.

Only 1 or 2 mobile VCT are left and the VCTs in hospitals report HIV positive cases to NAP. (Skype interview on 26th of May 2015)

In an interview in May 2015, UNFPA's response to the question of why the funding was stopped was

UNFPA stopped funding the VCTs under NAP management in 2013 because it is NAP's responsibility to secure salaries for staff working in VCTs under their management. We secured the financial demand to train and provide technical support to staff in the beginning of VCTs. But now, the VCT staff is MoH and NAP staff and their salaries should be budgeted from NAP operational plans and national work. Yes, we didn't have an exit strategy on how to cover the financial support for VCTs in NAP, however, we are present in almost all technical meeting and consultations related to the policies drafted from HIV and AIDS response in Egypt (Personal interview, May 2015).

Provider-initiated testing and counseling was introduced in the National AIDS Strategy (NAS) 2012. Basically it means that all individuals receive a routine offer of an HIV test recommendation from medical doctors. It is stated that this intervention will be implemented in all tuberculosis clinics, 50 antenatal care clinics and 20 clinics that treat sexually transmitted infections by 2016 in four governorates. (World Health Organization website)

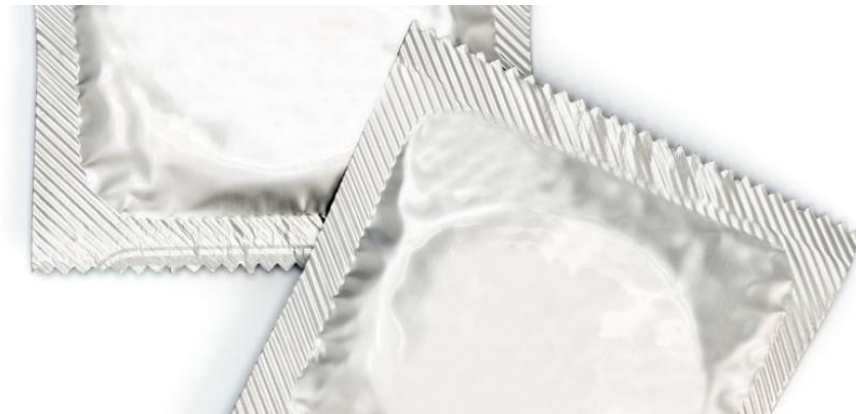
However, what is the influence of this intervention on the three pillars of voluntary testing, namely informed consent, counseling and confidentiality? From a public health perspective, it is promoted as a cost-effective intervention to detect the virus in the blood, which would help in the introduction of early treatment, and medical intervention. That will lead to positive health outcomes and will contribute to the efforts to control the virus as planned by the NAP. Thus, it will be beneficial for the individual health and public in general.

The question here, if implemented, how will it affect the preconceived judgmental ideas about HIV and AIDS at the social level? Those ideas have contributed tremendously to the stigma and discrimination associated with HIV and AIDS. There are no details about the dynamics of the process of the implementation of provider-initiated testing and counseling and my interlocutors did not go through it. However, I tried to imagine a person seeking medical help and getting recommendations to do blood test for HIV. Considering the medical authority of the healthcare service providers, how can we ensure that informed consent is being

exercised in this situation? In National AIDS Strategy, it is mentioned that healthcare service providers will receive trainings to reduce stigma between health workforces and to develop their capacities on how to do counseling. However, would the public health facility (clinic for example) have time to provide pre and post counseling? In which ways confidentiality will be granted for the person ensuring his/her rights on who should know his/her HIV status? Furthermore, provider-initiated testing will be implemented in 50 antenatal care centers. This means that women will be targeted more than men, considering all the structural gender inequalities deeply constructed in Egyptian society. Guidelines were issued by WHO and UNAIDS to specify the framework for the implementation of provider initiated testing and counseling. The guidelines focused on the three pillars of voluntary testing, however, what measures would be put to ensure the presence of those three pillars of confidentiality, consent and counseling given the shortage of staff number, capacity as well as friendly attitudes'?

I acknowledge the difference between mandatory HIV testing, which is performed without the consent on the person and with no counseling and provider-initiated testing and counseling. However, I believe that the process of the implementation of the provider-initiated testing and counseling needs to be examined. It can turn into mandatory testing without informed consent of the person, or under pressure. Egypt is a low prevalence country and provider-initiated testing is performed in high prevalence African countries, United States or Canada, so issues of consent and confidentiality can be overlooked or underestimated.

And while we are preventing



In the National Strategic Framework, the government called for implementing harm reduction intervention for substance abuse. Harm reduction basically means reducing the harm in the case of sharing needles and unprotected sexual conduct, through distributing condoms and clean syringes along with information on how to use them. It is an intervention that is usually accompanied by raising awareness activities to share correct information about HIV and AIDS. The question here is: what are the measures that will be implemented to protect people who are targeted through harm reduction programs? People who inject drugs are imprisoned; moreover, people who carry clean syringes (Oraby, 2013) on the streets can be imprisoned as well. At the same time, carrying condoms or using them has its taboo because it indicates sexual conduct outside marriage, which is regarded as profane, sinful, and against the morality of the society. Condoms are usually thought of as a birth control method between married couples. In other words, in a country that is considered conservative and oppressive (the security apparatus tends to devalue the human dignity and life), how can harm reduction (providing clean syringes and condoms) as a controversial intervention be implemented? Moreover, what are the terms that grantee the safety of a person who is injecting drug or unmarried and in need for a condom or a clean syringe? In the National Strategy, it is written that the National AIDS program will enhance collaboration with other governmental entities to facilitate the work and process of stigma reduction. The Ministry of Interior was one of the approached partners in an outreach program-targeting men who have sex with men and sex workers (UNAIDS, Global AIDS Response Progress Reporting (GARPR), 2012). In the Egypt draft concept note for the Global Fund grant developed in June 2015, Ministry of Interior is one of the entities that will be approached to discuss and implement harm reduction activities with them. However, in cases of misconduct, especially from Ministry of Interior side, who would be questioned or hold accountable?

The issue of addiction to drugs is not the main focus of this document, however, in the coming few lines I would talk briefly about it in relation to harm reduction as an approach. Harm reduction techniques still need to address the issue of

²⁵ <http://www.madamasr.com/news/ministry-investigate-ngo-over-awareness-programs-same-sex-partners>

attitudes and stigma around HIV and AIDS, because it can not be assumed that “harm reduction will lead in particular to more humane society and conditions” (Roe, 2005). The provision of clean syringes places the sole responsibility on the person to take cautions and protect his/her health from viruses, however, it is still a pragmatic short term solution that works to relief the symptoms of bigger social, economic and political problems and gives no room to “critique political, legal and social systems of power that create the harm” (Roe, 2005). For example, during my fieldwork, I have encountered people who are part of the outreach teams in harm reduction activities who confirmed that drug dealers, in Egypt, distribute clean syringes with the drug itself and people who seek the drug can take clean syringes and do the injection on the spot. Particularly this is done in certain places outside of Cairo on the desert roads. It was a point of great surprise to me, first because it was assumed that clean syringes are from pharmacies or the very few sites that provide harm reduction services, not from the drug dealers and the whole dynamics of having a semi-harm reduction site at the dealer place was inconceivable to me. So, why people who use drugs would leave the relatively “safe space” at the dealers gathering and seek an NGO to get a clean syringe from was one of the questions that confused me. It is evident that police can arrest people who carry clean syringes in the streets (Oraby, 2013), in addition to the banal and ineffective approach of dealing with addicts and substance abusers as either diseased bodies or criminals. In both cases excluding the person who take drugs in prisons or rehabilitation centers and hospitals did not provide great help in quitting the drug. Up to my knowledge, in Egypt as well as prevalent globally, drug addiction is dealt with whether as a disease that needs hospitalization like treatment or as a crime that result in imprisonment and jail. Both approaches proved inefficient in dealing with drug addiction and many people get back to use drugs after their isolation periods in rehabilitation centers for example. Realistic and alternative techniques to study addiction and its multiplicity within different people are still far from realized on the ground. The generalized and one solution fit all theories of addiction are monopolizing the scene of the addiction to drugs. Harm reduction is a progressive approach, but it has the essence of neoliberal economy “that indicates the political will to address social disorder and decrease the expenses in legal and medical services... through medicalization of the social and political problems in the governance of the margin in the neoliberal state” (Roe, 2005). Clearly, the margin here is the people themselves who escaped to drugs. I

adopt the position of encouraging harm reduction techniques to be available, however, realistically examining how it is being implemented or how it can empower larger rooted systems of political and economic harm is lacking from social research scene.

It is stated in Egypt concept note for the Global Fund grant that the first challenge to providing prevention services to “key population” is criminalization. There is full acknowledgment of the low chance in changing laws and increasing security and police raids on gay people and people who inject drugs as well as sex workers. However, the concept note stated that activities targeting those “key populations” would be designed to protect them and the outreach workers and liaising with local police offices to protect them. Here, I find this coordination with police worth worrying, giving the oppressive and inhumane raids documented by national media on gay people for example. At the same time, the work of the outreach workers would be jeopardized and edgy. And the question here, what can be done to ensure that people who are addressed with those services remain protected and interested in seeking information and services from the outreach team?

The new strategy was attentive to the fact of the need for a proper procurement and supply management plan for treatments and testing kits needed for monitoring the virus and its progress/ recession in the blood. It was acknowledged that many people who test positive do not go back for checking the other vital and needed tests like CD4 cell count to know the status of immunity system in the body. The proposed solutions would be more decentralized sites to offer the CD4 and viral load testing in a friendlier atmosphere. The CD4 testing is crucial to know the count of the immunity cells protecting the body and to start the HIV treatment of less than 500 cells according to WHO recommendations. The new strategy mentioned that there is a possibility of initiating the HIV treatment once confirmed positive diagnosis to avoid the waiting period or the decline of many from doing CD4, which might affect their health conditions. I find the later a realistic solution, yet it needs the timely procurement process and request for enough HIV treatments at the Ministry of Health stores. Dr. Ahmed Khamis shared his opinion:

Now it is the time to be more critical to what is happening in HIV response in Egypt. I will not blame people at need to seek money or treatment. I blame NGOs that lack coordination between them. And blame donors who don't monitor properly how their money is being spent. We should have a critical look to evaluate the quality of services and make sure that we didn't lose the

track and aim of our work. Service providers should enhance their communication and come up with complain mechanism to monitor and document any misconduct whether in governmental or non-governmental organizations. (Dr. Ahmed Khamis, Skype interview on 26th May 2015)

The most major and severe constraint mentioned in the document is stigma and discrimination toward HIV and AIDS and its effect on people living with it. It hinders them from accessing vital support services including the medical services. The concept note indicated the need for future activities to “enable” the environment through providing safe space for treatment and legal services on demand basis.

The imagined ideal type of a medical doctor or a health service provider used to be perceived to be “an angel of mercy”. However, when it comes to dealing with a person that doesn’t fit in the personal and collective moral code of the health service provider, would they still be considered as an angel of mercy? Equal access to proper healthcare services in Egypt in general is highly questionable with many lines under the word “proper” as a concept and practice. The stigma related to HIV and AIDS is a symptom of a chronic social problem which is the merge of lack of knowledge added to the tendency to act on prior judgment, prejudice and discriminate against people who are perceived to be opposing the moral code of the society. Moreover, when it comes to healthcare service providers and their medical code of ethics, what danger lies in favoring the “public interest” over the “patient interest”? What drives them to take a decision of disclosing a status of a person living with HIV and break confidentiality (Appel, JM 2006) keeping in mind that the boundaries between public and private interests are not a given, but are subject to continuous remaking and analysis. Hence, the site of medical care provision is a site to examine the “biopolitical” and its manifestation. In this site, the representation of social and medical authority can be represented in one person who is the healthcare provider. Additionally, the person living with HIV is going to “unpredictable” site. In other words, the reactions of health care service providers to HIV will never be predicted as they would provide the healthcare service with humane attitude or not. Hence, the person seeking help is in such vulnerable state of not understanding medical terminology, the threat of being exposed and humiliated if the health service provider decided to do so in addition to the health condition that he is suffering from.

Attack on prevention

In an article published in April 2015 on a national online newspaper, the news about investigating the NGO was spread. (Madamasr Electronic newspaper). The article mentioned that a complaint was presented to the ministry from a “concerned citizen”. The argument was that the NGO violated article 11 of law 84 (2002) regulating NGOs which states “Associations shall not be allowed to conduct any of the following practices or activities: Threatening national unity, violating public order or morality.” The ministry issued a statement and stated that the NGO will be closed if found in breach of the law, which didn’t happen eventually as stated by the NGO manager above. The concerned citizen, in the complaint, presented a video filmed secretly at the NGO of a teaching session by staff of how to practice safe sex between same sex partners to get protected from sexually transmitted diseases. The article presented the opinion of medical specialist who argued: “The ministry may do as it pleases in accordance with the law. However, as it cannot end or change people’s sexual orientation, it should strive to promote safe sex, for the sake of public health and national wellbeing.”

Our work is at stake. There is no enough coordination with different ministries including the Ministry of Interior and the Ministry of Social Solidarity. We work very well with the Ministry of Health especially the National AIDS Program. The new NAP manager, Dr. Walid Kamal, was of a great help when we had a problem recently with the Ministry of Social Solidarity. We found people coming from the Ministry of Social Solidarity to investigate the work in the office. One of them had a mobile phone taking pictures of all the posters that present information about HIV and AIDS and safe methods of injection for the harm reduction component of our approved work. One of the three staff from the ministry had offensive attitude and judgmental looks all around. We later learnt that there was a complaint about our work that we promote promiscuity and violate the laws. The issue was sorted out later through the help of Dr. Walid Kamal and his support to our work and efforts in raising awareness about HIV and AIDS. We adopt the harm reduction approach and we are part of a network of national NGOs working using harm reduction approach. We provide clean syringes, condoms and information about HIV and other sexually transmitted diseases. The NGO was founded in 2009 and this office we are sitting in, like a drop in center is a comprehensive care center based on 5 pillars to address the issue of HIV, including counseling, HIV testing, peer education and outreach team and clinical care for sexually transmitted infection. In 2009, the psychiatrist responsible for the NGO tried to have a kind of agreement to give a general idea about our work to the local police officer to facilitate the work of outreach but no official memorandum of understanding was signed. We don’t have a memorandum of understanding with ministries such as health or social solidarity. (Manager of the NGO in

Giza, one of the sites of this research)

Prevention work is done mainly by non-governmental organizations especially to people who inject drugs, men who have sex with men, and female sex workers. Services based on behavioral change interventions (using condoms and clean syringes), voluntary counseling and testing for HIV (only rapid testing that detects the presence of the antibodies of the virus and then the person is referred to NAP program services), and clinical care for sexually transmitted diseases (HIV National strategy 2015-2020). The condoms are available in both governmental and non-governmental facilities; however, clean syringes are only available in non-governmental facilities (HIV National strategy 2015-2020). Home-based care is provided, but is also limited to clinical care (Interview with UNAIDS coordinator and the aforementioned NGO manager).

There was an NGO called Friends of Life established and run by people living with HIV in Alexandria to serve their needs and communicate their medical and legal demands to policy makers. However, it is not active anymore. Internal politics and conflicts of interests found their way between the people inside it and couldn't survive till now. (NGO manager, personal interview spring 2015).

Indeed, there is no independent NGO representing people living with HIV and “key populations”. However, they participate in outreach activities and consultation meetings only through other civil society organization working on HIV and AIDS (National AIDS Program, Concept note, June 2015). Working with commercial sex workers remains challenging due to the lack of data and social stigma. However, there is one NGO run by women which provides prevention, medical and legal support to female sex workers (National AIDS Program, Concept note, June 2015).

People who work in outreach, especially with the three groups forming the key populations, are prone to get arrested or at least harassed by police officers. The complaint presented to the Ministry of Social Solidarity indicated that we are under threat of closing anytime under these uncertain circumstances. Last time we were lucky to have the NAP management on our side. (NGO manager, Spring 2015)

The uncertain and insecure atmosphere in which civil society organizations operate could affect their autonomy and ability to reach out for more people. Moreover, it can affect their funding opportunities as they can delay or slowdown

their work in the field (National AIDS Program, Concept note, June 2015). Whilst, the operationalized plan for HIV and AIDS in Egypt has the scheduled outcomes to minimize the risks and achieve “public good,” the political, economic and social atmosphere is highly volatile. Changing decision makers and policy planners in Ministry of Health and other ministries for example in addition to the precarious violent work of the security apparatus are part of that volatility. Women and their vulnerability to HIV were not emphasized in the National HIV Strategy. It was more mainstreamed within the activities as most of the prevention fund go to key population as mentioned before. Globally, women constitute more than the half of all people living with HIV. The prevalence rate of HIV among young women aged 15-24 is twice the rate of young men in same age group (UNAIDS, 2013)

Egyptian Women and HIV

Women are more vulnerable to get infected with HIV than men due to different biological and social reasons. Biologically, women can contract reproductive tract infections more than men due to the biological difference of their genital and reproductive systems. This makes them at least twice as more at risk of contracting HIV during sexual intercourse than men. They do not have access to cheap female condoms and they have to negotiate using the male condom with their partners if they were aware of its protective benefits. Women face different forms of violence and suffer from structural barriers such as poverty and lack of access to education and knowledge and stigma. Needless to say that women who work as sex workers or who inject drugs are suffering from multiple forms of stigma and exclusion that deeply compromise their access to health care services especially related to HIV and AIDS like voluntary counseling and testing centers (UNAIDS, 1998).

Egypt’s Demographic and Health Survey sample for 2008 included 12,008 Egyptians (6,290 women and 5,718 men) aged 15-59. They were asked questions that measured their basic knowledge, attitudes and prevention practices related to HIV and AIDS. The findings showed that the number of people with basic knowledge on methods of HIV prevention was low. The percentage of women and men who have a comprehensive understanding of HIV and AIDS (know the use of condom and having an uninfected faithful partner can reduce the chance of getting AIDS; understanding that a healthy looking person can have HIV which is the virus causing AIDS) is

limited. Only 7% of women and 18% of men have this basic knowledge about HIV /AIDS. Only, 18% of women and 37% of men interviewed and aged from 15-29 years old were aware that condom use can reduce HIV infection. Even in younger generations aged 15-24 years old, only 4.8% females and 18.3% males have comprehensive correct knowledge of HIV and AIDS. Overall, 99% of respondents have negative attitudes towards people living with HIV. The source of information is mainly TV, with only 2% of respondents acknowledging getting information form public spaces such as seminars, campaigns and workshops.

Overall, 99% of respondents have negative attitudes towards people living with HIV. The source of information is mainly TV, with only 2% of respondents acknowledging getting information form public spaces such as seminars, campaigns and workshops. The level of education of the respondents played a key role in acquiring the basic knowledge of HIV and AIDS. Even with higher education women remain less knowledgeable about the virus (12%) than men (26%). The interesting part is that uneducated women and women with primary education were more willing to care for a family member with HIV than women with higher education with 27% to 22% respectively. Regional disparities in knowledge level and access to services were remarkable. Women and men in rural areas have lowest percentage of HIV and AIDS basic knowledge and prevention practicesⁱⁱⁱ.

I have a personal experience related to women and their attitudes while getting information related to HIV and AIDS. I have been working in the field of sexual and reproductive health since 2001 on voluntary and professional levels. During one of the workshops that I was conducting, I had 18 young people from 18 to 25 years old participating in a workshop on basic knowledge on HIV and AIDS in Alexandria. We had 8 females and 10 males coming from universities to get information and work as educators for their peers. It was held in Alexandria in March 2013. Two of the women who were 23 and 24 years old with a bachelor degree withdrew from the workshop because they felt that the information related to HIV and AIDS was not appropriate. They went on elaborating that they will know that information from their mothers and future husbands when they get married. Despite being just two participants, I found this situation alarming especially that it was the first time such a situation happened, and that these two young women and me do come from middle

class and educated families. I respected their choice and offered to give them the information on a personal basis but they were satisfied only with brochures that state some facts about HIV with noting mentioned about other cross cutting issues related to sexual health^{iv}.

Promotional materials that disseminate information about HIV and AIDS are widely used to assist prevention efforts. In an interview with UNFPA staff in May, I asked about the process of developing, for example, the latest brochures used in HIV awareness raising activities. The response was:

We conduct a series of consultation meetings with people that we target in our activities. For example, if we are targeting young people, we invite them to brainstorm on the content and we develop it with the help of external consultants on media, graphics and so on. After the development of the brochures, the appropriateness of its content within the mainstream cultural context is always our job in the office to decide. We work with governmental entities and mainstream people. Hence, we should be aware about the language used in our materials. For example, when writing about safe sex and using condoms, in our last brochures, we mentioned “between married couples”. No, we don’t usually do group discussion with different young people to test the brochures’ content after the production. (Personal Interview in May 2015)

Attitudes towards the language used in disseminating information about HIV and other sexually transmitted disease may differ variously. Some, people would only take it literally, as condoms only between married couple or for vaginal sex, and others might understand the sublime message between the lines. It depends on the background of the brochure reader and ability of relating to it or not. However, is that totally “educative” or transferring “clear and realistic” information? The juggling between “words” and presenting “clear” information is one of the issues in written materials on considerably sensitive topics as such.

Amal, one of the mothers, volunteers with one of the NGOs to work in outreach team and help newly diagnosed cases. She has an experience related to being involved with civil society addressing HIV and AIDS.

In the past couple of years, I became more involved in civil society and outreach teams to help those newly diagnosed with HIV. I talk to them from my own experience and share with them my journey of living with HIV and

raising my children for the past 9 years. Not all civil society organizations are the same. Honestly, I feel sometimes that we are used in their activities to get more money from the donors. For example, I was part of project of teaching sewing and designing clothes for women living with HIV with one of the NGOs. At the beginning we were very excited to learn a craft that will help us support ourselves and generate income for our families. The project started well and we started to learn the basics of sewing and they told us that our work will be marketed and sold and we will gain profits. Two months later, the project started to fade away. The place they rented for us to learn sewing in was very far, I didn't mind though. The dates and times of the sessions were changing and I was trying to manage how to find someone to take care of my children. Later on, I stopped going and I knew from my colleagues there that they stopped as well. They were giving us money every time to go as transportation money. I would try to attend to take this money and save from it as I didn't have any job. Couple of months ago, the project manager called me to go and to collect other women who stopped going because she had a visit from the donor. I didn't go. I told the people I know to go because I knew they need any source of income, even if it is the transportation money. Later on, I knew that many of them didn't go and the project managers arranged some women who are not even living with HIV to show them to the donor. (Amal, Spring 2015)

I will borrow the quote, because of its relevancy and interconnectedness, of Dr. Ahmed Khamis, UNAIDS country coordinator, which was shared earlier here when he said,

I will not blame people in need to seek money or treatment. I blame NGOs that lack coordination between them. And blame donors who don't monitor properly how their money is being spent. (Dr. Ahmed Khamis, Skype interview 26 May 2015)

In the interview with Dr. Khamis, the questions of access and working with NGOs were raised especially, while working with women and mothers living with HIV.

Last month, we conducted a gender assessment to understand the gender gap and enhance gender mainstreaming in the National AIDS Response. It is a fact that women lack access for the services needed to prevent and or support their living with HIV. We are piloting two treatment centers and promoting them as sexual and reproductive health centers and keen to have more compassionate and understanding staff there. UNICEF is the leading UN agency in Egypt on implementing programs to prevent mother to child transmission of HIV. We are trying to respond to other social and economic as well as psychological needs of a person living with HIV and started being aware that our interventions need to be more practical to their other needs and not only reduced to HIV treatment and care. However, we keep trying as we are not working in a vacuum and have many partners who are strategic and field oriented and we all need enhancement in

being coordinated and timely in our response. We should be aware of how specific problems of mothers living with HIV can hinder their access to the treatment and pharmacies and if they face a particular problem in adhering to the treatment (taking it regularly and on time). The numbers of people living with HIV are growing. We are pushing for single pill treatment as many people should start at CD4 count of 500 as recommended by the World Health Organization. I admit that we need to look beyond the support group as a used technique to provide psychological support, because it doesn't work with everyone. (Dr. Khamis in Skype interview 26 May 2015)

Key population... the Key is for what?

Egypt has a concentrated epidemic “high prevalence rate” of HIV among “key population” group as presented in the literature sections and most prevention efforts and outreach are directed towards them²⁶. From a public health perspective, working with groups that suffer from prevalent disease and “controlling” the disease from infecting others is a must. However, in the case of HIV, and with full recognition of the importance of specific prevention and outreach measures, how does that contribute to the social aspect of it? To answer this reflecting on the circulation of the term “key population” as a platitude between people working in the field of HIV and AIDS is reinforcing that HIV and its sources come from specific groups of people, not from specific actions and human “behaviors”. This question came to my mind as a reflection from one of the mothers when she said

The question from where you got AIDS is always following me. I attended once a support group with people living with HIV. It was only women. One of the women started saying, I got my HIV from my husband who had blood transfusion in car accident. I found myself forced to say from where I got it and said from my husband too. She said, we all know what you husband is doing. I felt shame and was aggressive with her. The facilitator tried to calm us down. We all at the end living with it, but why some of us think we they are better than others. If I am not married, I would be more ashamed to live with HIV here in this country. I have a kid too, which is a kind of protection when I say I am a mother and I get a sense of respect or pity may be, but I don't care. Both better than looking down at me. The issue that HIV infect only people who use drugs or have sex with anyone or gay men still following me. (Samira, Spring 2015)

²⁶ Ibid

There is a thin line between emphasizing work on certain group to prevent and control HIV and calling them “key population” and the halo of “othering” that appears around them. Othering in terms of the subconscious perception that I will be immune if I am not from this group which can be deceiving. Othering in emphasizing certain populations over others which can be excluding from the mainstream and increases self-stigma and public stigma especially if those acts are not tolerated by the law or by “traditional morality codes” and claims that people, not the acts, are better or worse than others. Emphasizing on the “paradoxical coexistence between inclusion and exclusion, of emancipation of human and inhumane neglect” (Comaroff, 2007)

Just a look back at history of HIV and its “specific groups”, we check what Paul Farmer said in his book “*AIDS and Accusations*”. The history of blaming HIV on others is documented. Haitians were accused as the “walking AIDS carriers” by the United States and Haitians have responded back accusing the US with manufacturing the HIV virus as a biological weapon to get rid of all black people. All these accusations have contributed to shaping the mindset of the people to wonder what the origin of HIV as a virus although they haven’t applied that way of thinking on other microbes such as HCV and HBV. Being an HIV positive person leads to constructing a new social role in the society that the person lives in due to the reaction of the person him/herself towards their status and due to the actions of friends, family and colleagues (Lang, 1991). That would contribute directly to their morbidity status and hence the utilization of healthcare services due to the significant link between mental and psychological health and the immunity system affected by the virus.

The bio-political aspect of HIV lies in its multifaceted dimensions of how the disease is perceived as a taboo by the society and by people living with it along with criminalization of the acts that might lead to HIV zero-positivity as well as the direct link made since early 80s with homosexual acts. Variety of authorities at stake, such as legal, medical as well as social and religious are forming and influencing HIV positive subjectivities. Tailoring strategies and interventions that targeting particular groups of people termed “key populations” should be revisited to pause and ask questions on how this contributes to controlling HIV and AIDS.

It is not my aim here to analyze the dichotomy between the individual rights versus the state or the society as a collective hegemonic power. Rather, I am trying to deconstruct the “buzzwords” that are used in the domain of HIV and AIDS as a public health issue and already reflected in the national response to understand how it would affect the people living with HIV in the Egypt. Considering the particularity of the country and its political, economic and social structure, concepts and measures related to HIV and AIDS should be articulated and implemented in a way that acknowledges the real situation on the ground. Between the concept of “controlling HIV as an epidemic” and the concept of “individual autonomy and informed consent”, what are the gains and the losses on the individual and social levels? And assessed by whom? How does the state draw its policies taking into consideration the multiple levels of shades and complexities between what is called “public interest and individual interest” especially when human life is involved? I mean human life in all its aspects including the social one. Particularly, who decides that one interest is more important than the other?

Concluding remarks

Looking at the official documents from Deleuzian lens, led to examining the concepts/interventions mentioned in the documents such as “controlling the epidemic”, “promoting HIV testing” and “implementing provider initiated testing and counseling” within the Deleuzian concept of “Society of Control”. To start with Gilles Deleuze (1992) who argued in his article titled “Postscript on Societies of Control” “that the concepts of governmentality and disciplined societies that were developed by Foucault are now transformed into societies of control” (Deleuze 1992). He stated that this transformation happened as an evolution of the concept of discipline into control. He went on saying that people are reproducing and practicing discipline that has been practiced upon them in their families, schools and governments in a normalized way even outside of those well-identified institutions (Deleuze 1992). So, it is more like “controlling” one another and reproducing discipline in multiple forms. I find this concept relevant to analyze the way HIV is being addressed at the national level especially after reading the official documents developed by the government to address HIV and AIDS. The Deleuzian explanation while living in the neoliberal social structure that we live in now provided an analytical lens on how diseases, and hence people living with them, are being controlled. However, the lives of the people

living with HIV are not static and are not being reconstructed once and for all under the influence of their HIV positive diagnoses. Their lives are continuously changing as individuals and are influenced by the surrounding social, political and economic environments and having the virus causing AIDS is one of the burdens that they carry along with sustaining their living.

It is a representation of how, in public health measures, numbers and statistics are the things that reify the progress or the pitfalls of those measures. Hence, this body of governmental and international entities would talk about cost-effectiveness comparing the number of people targeted to monetary numbers. In the meantime, the human life with all its complexities and various aspects will be silenced in between those numbers. Therefore, Deleuze argued that, in a society of control, the individual is dissected into even smaller units of cells and genes and the individual as a whole is overlooked. Hence, the control became more diffuse and fluid in the layers of the world that we live in no matter if we are part of certain hierarchal regulatory institutions or not. As Deleuze stated “there is no need to ask which is the toughest or most tolerable regime, for it is within each of them that liberating and enslaving forces confront one another. There is no need to fear or hope, but only to look for new weapons” (Deleuze, 1992). However, which new weapons were meant in that quote? I did perceive an imaginary of those weapons, in this specific context of the research interlocutors, which are the techniques of negotiations or bargaining with the interplay of different authorities they came to encounter. Whether they were prepared to live with a generally “perceived” taboo organism within or not, their will to live was tangible and their techniques are constantly mutating. In their reflection on religion, talking to god and how do they interpret their dreams as well as in their determination on having children and raising them. Their negotiation process goes parallel to their internal as well as external dialogues with HIV or medical, social and legal authorities. Hoping for, as Joao Biehl said “The body- real or imagined, living or dead, present or hypothetical can mobilize scientific communities and patient populations in equal measures around quests for profits, knowledge, justice or simply the will to live” (Biehl, 2007).

The coming chapter will narrate their stories in encountering birth, death and the entanglements of hopes and fears in their present. It will give an idea about how they perceive motherhood and maternal subjectivity.

Chapter Five: Mediating the social along with Lamented moments and desired ghosts

Remembering *Heba*

I wanted to get pregnant again and give birth to another girl to compensate me from the baby girl that I lost. I have two other children, teenager boys now, but I know that a girl will be a support for me and the genuine kindness and warmth of girls are what I need in my life. Sara is almost 6 years old now and she looks like her elder sister that I lost. This is a photo of Sara as I always carry it with me. Her elder sister, passed away 7 years ago. Her name was Heba and she was almost 10 months when she passed away. Heba got very sick and I was spending nights in children hospital with her and doctors were not able to know the reason of her diarrhea and sickness. She was not able to breath normally and had always difficulty in breathing and they said it is pneumonia. I could feel her breathing well only while I am breastfeeding her. I loved the moments of breastfeeding her because I felt that during those moments she was aware and connected to me. Her father back then would come to visit us at the hospital and leave. One night at the hospital, I was praying and talked to God saying, I just need to know the reason of her severe illness, please enlighten me and that doctors know the reason behind her illness to be able to treat her. After my prayer, I went and changed her diapers. I noticed a lump in her inner thigh under the skin. I started checking her small body and found another one in her armpits. I had the same lump behind my ears but I didn't pay attention to it and I wear a scarf so, no one of the doctors can notice it. I looked at Heba and talked to her saying "may be this lump I have is what you have". I carried Heba and went to the doctor who was staying up late in the hospital that night. She is a very kind doctor and was following up with Heba's case all the time. When I showed her the lumps in Heba's body and the one I have behind my ear, she said we will do another blood test in the laboratory in the morning. The morning after the doctor came and took Heba and said, the blood test is not in this hospital and she will take her to laboratories in Ministry of Health. Same day, the doctor told me that Heba has AIDS. I almost fainted and she took the child from my arms. I was alone, so I called her father on the phone to come and told him on phone that Heba has AIDS. He was shouting on the other side saying from where she got it. I ordered him in loud voice to lower his voice as he was at his work place and no one should know about that. He arrived to the hospital with his mother and my sister. Can you imagine! He brought his mother and I just told him not to tell anyone. Before his arrival, I managed my emotions and myself and had a talk with the doctor. The doctor said that nothing she can do for Heba and I should take her home to rest and spend her days between us peacefully. The doctor said that I should do the blood test and my husband too. So I packed our stuff and waited for Heba's father in the reception of hospital. When I saw him coming, I told him lets go home and we did. In the meantime, I was angry and frustrated that he brought his mother and my sister. My sister kept asking me, from where your daughter got AIDS on our way back home. My sister was panicking and said that for sure my daughter got the disease from me. My sister helped me and was present while I was giving birth at home to Heba. My sister kept crying and said that she for

sure got AIDS too because she was involved while I was giving birth. When we arrived home, I had a talk with Heba's father that we need to do blood testing for us and for the two boys as the doctor advised. I don't know from where I had this strength to be that practical. When I think of it, I feel there was a different person standing there, not me, who carried herself and her daughter and was calming people around and acting, as she knows what she is doing. We did the blood testing and the boys were healthy with no virus but Heba's father and me had the virus. I went to my mother's house with Heba after I got the results of the tests. I told my mother that I don't have the virus and for sure Heba got it from blood transfusion at hospital. My mother was very happy and prayed to thank God. I told my husband on the phone, in front of my mother, crying that we are healthy and we don't have the disease. What was I supposed to do? Heba's father told both families about Heba's disease. My sister was crying all the time and said her husband will divorce her if he knew that I have AIDS and she might be infected, as she thinks, too. I had to manage the circumstances in that particular time and then God will help me to see what I will do in the future. My priority was Heba at that time. She was dying, I felt so, and I wanted to spend as much time with her as I can. I took Heba to a room and put her on the bed and started praying asking God to enlighten me and give me patience to handle all of this. It is one of the prayers that I would remember the most in my life because I felt God was really listening. I said back then "God, Heba is your gift. If you are taking her, give me patience to handle her loss as another gift". My prayer sounded like negotiation with God to give me patience instead to endure all this and to relieve Heba from her pain in the best ways possible. Staying in hospitals and her sickness were not easy for both her and me. The day before Heba passed away, I took her to studio to take photos for her. I noticed that I don't have pictures of her and when the photographer asked me to wait till she recovers, I told him; no take the picture anyhow. On the day she passed away, I was home with her and called my mother to buy ventilation machine because that day she couldn't breath at all. I took her to small clinic near by and while we are in the taxi she passed away. The doctor confirmed that. I was calm. The immediate thought which came to my mind was this "please, god compensate me with another girl". I was breastfeeding her. This thought never left my mind, especially when I knew that this disease can be transmitted from breastfeeding. I kept telling myself that may be she was born healthy and she got the virus from my breastfeeding. (Amal, Spring 2015)

Amal, gave birth to her second daughter almost one year after the death of Heba. She experienced the fear of transmitting HIV to her child and wanted to end the pregnancy. She started going to the National AIDS Program to do the testing and informed one of the doctors there about her fears and feelings towards giving birth. Amal Said:

I didn't have much information about how can I protect my coming child from HIV. The pregnancy encouraged me to seek help from the place that provide me with treatment and know my case. I went to one of the doctors

there and told him how much I want this child as much as I fear transmitting the virus to her and wanted to do abortion. The doctor encouraged me to keep the fetus and I was monitoring the progress of the virus in my body through blood tests. I was taking medications regularly and taking care of my health, however, I was resorting to praying all the time to have a healthy child. I was feeling she would be a girl who will compensate me. I gave birth and the baby didn't have HIV. I knew then that God is on my side. (Amal, Spring 2015)

To describe Amal, I was surprised to know her real age because she definitely looked younger than being in late 30s as she said. Her other two boys are teenagers. Her strong, outgoing and friendly voice challenged my perception about her petite beautiful outside. As a matter of fact, I was expecting more soft voice and a less firm handgrip. She was able to compensate the hidden expressions of her face with her captivating voice and strong eyes to the point that I forgot she is wearing a Niqap. As we went into the interviews, she uncovered her face and started telling the story of Heba's death and Sara's birth. The invisible barriers between two people who just met, can affect the direction of interview, hence, we spent time getting to make the conversation informal as a start. Later on, it moved to the point of mutual sharing of our stories both especially the one related to having children, giving birth and breastfeeding experience. Amal said:

I met journalists and researchers before, they used to come with questions prepared and papers and I would set and answer the questions with certain time. The interest in the detail and the sharing of our stories together made me more comfortable and eager to talk. The recording device or the papers that they use get in the middle and makes me cautious about what I say to them. Now, I lost the sense of this caution or anxiety because there is no devices nor continuous writing.(Amal, Spring 2015)

Amal's observations and insights of the way we shared our experiences in our unstructured interviews indicated that she was in a process of reflection. It resonated with the concept of intersubjectivity in communication and in anthropological research (Duranti, 2010). Alessandro Duranti navigated the concept of intersubjectivity according to Husserl in conversation with different scholars in his article titled "Husserl, intersubjectivity and Anthropology, 2010" as more than a mutual and shared understanding to include the process of reflection, because when reflection is missed, a strong pillar of intersubjectivity is missing (Duranti, 2010).

Amal was eager to listen too in our engaged conversation. Our stories of how we experienced the bond with our children through breastfeeding were center of this experience. Amal said:

Heba used to breath well when I am breastfeeding her, it was as if we communicate with no talking. The thought that I might have transmitted the virus to her without knowing that I am having it comes to my mind very often and I am not over this thought yet and I felt guilt. However, I tell myself; those were the only moments that she would seem like a healthy child who breathes well and aware of me. (Amal, Spring 2015)

Amal, as well as the mothers in this research, visit an organization that does group meetings to share information and provide psychological support to people living with HIV. Those groups called Support groups; we will talk about them later in this chapter. I asked Amal if she was able to share her experience and guilt feelings towards her child, she said

I try to focus on learning how to deal with my disease as this current time to be able to take care of my children. We are group of people who try to talk about their problems and concerns in assigned time. Those details of my past experiences are from the past. (Amal, Spring 2015)

Amal later said:

It was my decision to keep the baby after being assured from the doctor. Heba's father was not part of the equation especially, I was the one handling the loss of the child and calming our families at the time we discovered that Heba had HIV. I knew that Heba's father would not be supportive, he was never up to his responsibilities to the family. However, I wanted to give birth to the girl because I knew she was God's response to my prayers too to compensate my loss. I wanted to feel that I could give birth and take care of my children. Four years ago, I divorced Heba's father. He didn't change. He was having the same reluctant and infantile attitudes towards us as a family. One day, we were in Eid Holiday and he was staying at his mother for Eid days and didn't leave money at home. I borrowed money and cooked for my children and right after the Eid holiday, I went to Family court to divorce him. I met a young lawyer, she was very supportive and listened to my case. I actually felt safe to tell her that I am living with HIV and told her the whole story. I asked her to help me get divorced because it was a final decision. The lawyer called my husband and asked him to come to the court. He actually came and finally signed the divorce papers. He was crying, it was one of the few times I see him cry. I went back home and knew that my children were enough for me to keep me going. The children were not sad that I asked for divorce, I told them before going to court. They had witnessed our lives together and that was enough. After those years, I finally came to resolution with how I feel towards him. My resentment towards him was over, he is the father of my children after all, but I will not get back to him. Till now I think, how did I get the courage and do this step of seeking divorce and going to

court myself. I got married again from a person who is living with HIV. However, I asked for divorce. I thought he will be helping in the finance of the house, but I was again the one who is trying to secure the money for us; as if I was having 4 children not 3. Now, I am not thinking of marrying again, my children are my life. (Amal, spring 2015)

Invisibility in Life and death

My younger brother visits me in my dreams. Of course, I get very happy when I see him in my dreams, since he passed away 4 years ago. He used to stand in my side if I had any fights with my husband or my mother and was very kind and compassionate in dealing with. He was in jail when he died, in 2011. Do you remember when they said on TV that prisoners were causing a lot of riots and escaping the prisons? My brother was in prison for committing robbery and he was killed on 28 January 2011. General Batran was killed also that day and all TV channels and media were talking about it. One of my brother's mates in prison said that the guards who came inside and gave them clothes and opened the gates. My brother came to my dream that day wearing trousers and a white shirt, putting a scarf as a headband and his face was red as if he was running. He used to do small robberies with his mates and got caught before and my mother would kick him out of the house. She was always aggressive with him since he was a child and her solution always was to get him out of the house. He had a short temper but was the kindest to me and when he knew I am sick, he would check on me to take the medication and would buy nice stuff for my child. In the eyes of the people, he is a criminal, but I have never seen him this way. Although he is my brother from my mother side only, I always saw him as my kid and my support at the same time especially that he didn't experience kindness from my mother. My mother was angry at his father and got divorced and projected her anger on that kid since he was a child. The day I knew he died, it was the most major shock and trauma in my life, even more severe than the day I knew about my diagnosis. I don't talk about my brother's story a lot because he was jailed and died in prison. I know how people look down at prisoners and ex-prisoners especially that he was jailed because of robbery. Living with HIV as a secret made me more cautious of what I say and what I shouldn't say. I will not be able to take any bad comment about my brother because people can be cruel even on the dead ones. Complicated events and people did injustice to my brother in his life and in his death. (Sama, spring 2015)

Sama's story of the "invisible" death of her brother coinciding the "visible" death of General Major Mohamed Batran inspired me to search the details around this incident. I recalled the headlines of national media of the killing of General Batran in Fayoum by prisoners trying to escape on 28th January 2011. However, a web article

published on world affairs Journal²⁷ from the blog of Dr. Alaa Al- Aswany, Egyptian writer, documented the incident in May 2011. According to Dr. Al-Aswany, Batran's Family filed a report accusing two police officers of killing Major General Batran and presented it to the prosecutors. Dr. Al –Aswany mentioned that Major Batran was killed in Qat prison in Qaliubya governorate, in the northern part of Cairo and his crime scene was not investigated under the claims of unstable prison conditions that would hinder the work of the prosecutors. Furthermore, in Dr. Al- ASwany article, Batran's family declared that General Batran was fighting the Interior Ministry's plan to open the prisons gates on the 27th and 28th of January 2011 especially that he was fulfilling his duty till his death as the head of the prisons investigation department; a senior position in which he is responsible for all Egyptian prisons. Al- Aswany recalled the escape of almost 24000 prisoners that day that was allowed by Interior Ministry Officials, adding this fact to the black record of Interior Ministry led by Habib Al-Adli, that time, in killing protestors and kidnaping the people from streets to control January revolutions.

Media tales disseminated around the death of General Batran claimed that the prisoners killed him. However, in Dr. Al-Aswany's tale and in Ahram English Egyptian newspaper the following was mentioned "According to the second autopsy report prepared by the orders of an investigative judge and obtained by Al-Dostour website, police Major General Mohamed El-Batran was killed by one shot from above and that bullet was from single shot rifle"²⁸ confirming his killing by professional snipers who also killed more than 1400 protestors (estimates of the killed protestors are more than that)²⁹.

The entanglement of the national political events within the personal narratives of the mothers made me reflect on how stories are being told in newspapers and on TV channels in a way that alienate us from many details inside. The death of Heba, the baby daughter of Amal and the psychological and spiritual journey that she went through it made me wonder, how we read one sentence such as "her daughter

²⁷ <http://www.worldaffairsjournal.org/blog/alaa-al-aswany/egypt's-revolution-revisited-who-killed-general-batran>

²⁸ <http://english.ahram.org.eg/News/16890.aspx>

²⁹ <http://www.worldaffairsjournal.org/blog/alaa-al-aswany/egypt's-revolution-revisited-who-killed-general-batran>

died” and we can overlook it and continue reading. How her daughter died and how she lived that period of her life was visualized in the little details that Amal described as if it didn’t happen almost 8 years ago. The killed prisoners on the 28th of January 2011, among many others killed in Tahrir square and other areas in Egypt, were disposable and overlooked and turned into newline mainly to showcase the results of the transformation that Egypt is going through, into the unknown. Sama’s dreams of her brother consistent till now, but due to the eternal shaming of spending time in prison, she will always mourn him alone.

The consoling power of the Unseen

The art of escape appears magical, but it is the mundane, hard and sometimes painful everyday practices that enable people to craft situations that seem unimaginable when viewed through the lens of the constraints of the present. (Papadopoulos, 2008, p. 14)

Spiritual and religious thoughts and prayers were deployed in coping with loss. Sherin Hamdy in her book “Our bodies belong to God” examined the concept of envisioning the body as a deposit from God. (Hamdy, 2012). Hamdy examined the concept of preserving body and organ transplant culture and practice in Egypt indicating the internalized culture of “not owning our bodies” as it is ultimately owned by God. In this context, Amal’s prayer asking for patience to handle her loss indicates this religious fact and recognition especially during dire situations of chronic disease and frequent routine encounters with the Egyptian health care system (Hamdy, 2012). Yet, Amal’s agency and helpless hope stood out in her act of asking for patience and for another baby girl. She reflected on that as making a deal with God and negotiating with him in her uttered words. She took her reproductive decision and sought help from people who can help her, with an internal wish, to keep her child

Ghosts, I thought of Amal’s daughter and Sama’s brother as ghosts staying forever in their lives. Not all ghosts are indicating negative essence, but all of them are standing there with heavy presence, not visible except for the selected ones. The use of the concept ghost here is meant as “the absent-presences” that emerge in encounters with the “material, mediated, the sensual and the affectual” (Edensor, 2008)p331). I observed while Sama and Amal were talking about them, they were not bitter or resentful for the circumstances around the death of the brother and the

daughter. May be because of the time passed, I told myself, however, while Amal and Sama while talking about them, they were as if they can still connect with them somehow in their everyday lives and that they are not gone, once and for all through the physical death.

New paths for socialization

My son comes with me to the Ministry of Health when I go for the routine testing, or to the NGO when I go sometimes for the support groups meetings. I go to the support group because we talk about many issues that I can't talk about with anyone. There is some relief in knowing that all the people there, like myself, can talk freely and share about the burden of HIV. I changed a support group once and joined another one. The people in my old support group didn't ask about me outside of the group. I wanted to have a kind of support that is outside of the meeting room of the group in the NGO. When I am absent or having a trouble, I wanted other people who I can talk freely with to call me and ask; where you are, why didn't you come today, for example. I like my new group so much because they are very supportive people. Because we talk about different issues, I was able to know that I should complain about any mistreatment in the hospitals and how to do so. I got to know people in the NGO that can help me or provide me with recommendation that can facilitate the routine testing or getting medications. Even my perspective changed. I started questioning that what matters most not anything but kind treatment and you would never know the person unless you spend time with. (Sama, Spring 2015)

You did not see me 9 years ago; I was as naive as a little blind cat. I had to toughen up to take responsibility of my children. I was exposed to medical institutions, financial crises and family problems. Knowing that there is no one for my children, except me, affected my decisions and way of livings. I started looking for Gam'eyat (NGOs) to know more about my disease and how to protect my children from it. I went to group meetings and was helping people who were diagnosed especially women and mothers and visit them at home to talk with them. I learnt in the process about projects and funding for people living with HIV, I know that there are donations and a lot of money channeled for treatment. But, I still see the sufferings and sad stories of seeking medical care for example for many of us. (Amal, Spring 2015)

My interlocutors praised the interaction between people in the support group and the opportunity to discuss topics related to HIV, sexually transmitted diseases, how to take care of their health and strengthen their immune system. One of the mothers acknowledged that her attitude has changed towards homosexual people after getting the chance to spend time with people who are openly gay and attend NGOs' activities. She said "I used to have the same idea like everyone around me in my

surroundings, that they are bad people. It turned false. I have now friends who are gay and it is not my issue to concern about with whom people choose to partner with in their lives.”

The manager of the NGO described the work and number of support groups in Egypt currently in our interview. There are 9 support groups facilitated by NGOs in Cairo for Egyptians, one support group by the Hot Line for HIV under the National AIDS Program and one group for refugees run also by a NGO. Outside Cairo, there are two support groups in Alexandria, one in Minya, one in Luxor and Aswan. They are usually unisex groups and don't include people who are identified as sex workers or openly injecting drugs. The number of members of each group is 10 to 15 and they meet once a week. However, every member attends 15 sessions and then old members who attended 15 sessions leave and new members join. Every member who attends a support group receives a symbolic pay of around 20-30 Egyptian Pounds for the cost of their transportation. Each support group has a facilitator who runs the discussions between the people attending and they are trained on facilitation techniques and HIV and AIDS information with an NGO called FHI 360.

I noticed that social class affects the formation of the support group. For example, I had a person who is living with HIV, comes from upper middle class status, attended once a group meeting with people from different class, he was polite and completed the meeting. A couple of days later, he asked me to form a group with some of other people that he knows and living with HIV and all of them are from same class. Our aim in the end is that people would feel relaxed sharing their own issues and get support from each other. (NGO manager, Spring 2015)

Dr. Ahmed Khamis , UNAIDS Country Coordinator, expressed the need to talk about HIV treatment adherence and side effects in a more detailed and focused way inside the support group, he said:

People get medication, but treatment literacy should be enhanced. We have a problem in treatment adherence, because people get the medication but they have to take it daily at the same time. We are in the process to have the testing for drug resistance in Egypt because it is very expensive to be done abroad and people develop resistance and the drugs they take can turn ineffective over the course of their lives with HIV. HIV medications also have side effects, they are strong medications, and people need to know how to deal with the side effects and organize their lives in this regard. (Dr. Ahmed Khamis, skype interview, 26 May 2015)

Side effects of the HIV medication can be also a reason they don't adhere to the drug every day at same time. There are other societal issue like the need to hide the drugs in other bottles to be able to take it within their families or on public, some of them resort to rest rooms in public places to be able to take the HIV treatment (Khattab, The Agony of AIDS: A Qualitative Study on the Experience of AIDS in Egypt, 2010). Dr. Khamis indicated that UNICEF is responsible for implementing activities to limit mother to child transmission on the medical level. He said that UNICEF implements projects targeting mothers especially on the economic empowerment level. He said, "Children who are living with HIV would need group meetings and activities because many of them don't know that they have HIV and they should get support to have a smoother transition. UNICEF is handling this issue". (Dr. Ahmed Khamis, skype interview, 26 May 2015

The NGO manager said that there is an initiative by UNICEF in which people who are living with HIV act like a companion to newly diagnosed people with HIV, it is called health companion "*Rafeek Sehhy*". He described the initiative as helpful in two ways; it gives realistic and real understanding of the condition of living with HIV and it fulfills the people who are working in it on both economic and emotional way. They get training ahead on basics of counseling and update their information about HIV.

Amal talked about the consoling that she feels while sharing and relating her experience with other people and that keeps her enthusiastic about this initiative. However, while our talks about her feelings of guilt that would appear when talking about breastfeeding her daughter without knowing she was positive, she expressed that she didn't share the details of this feeling that appears once in a while. It happened with Sama and the story of her brother's death. The two experiences that they went through in their loss in addition not sharing it in detail remain incomparable and have a deep influence on their realities. Papadopoulos articulates this in his quote" Experiences which remain incommensurable and which cannot be assimilated are still integrally involved in altering the social conditions of our everyday existence." (Stephenson & Papadopoulos, 2006, p. 12)

Magda attended support groups and she expressed that would have loved to have them beyond the 15 sessions per member. She said:

Sometimes I take my younger child with me and sometimes not, but I liked going there. Even with the hassle of trying to find someone to take care of my children, I would have continued to go. It keeps me charged for the week and it is an opportunity to go out and talk freely (*fadfada*). I was thinking if they can have activities aside for the children that we have to accompany them with us while attending the meetings. They get older and can comprehend what we talk about in our gatherings. (Magda, Spring 2015)

The resort that the support group provides for the people to meet and talk weekly is obvious, however, some of them are constrained by physical illness, finding someone who can take care of their children or if the support group is far from where they live. They succeed in overcoming this for the sake of attending most of the time, but even after finishing 15 sessions of attendance, they still need these kind of spaces to express and share. It is a long process of rehabilitating their lives along with handling the burden of HIV among many others. And HIV burden mainly lies in the secrecy, stigma and new forms of socializations that it allows or inhibits.

Affective relations with objects

On the way to create new sideways for socialization with people, objects show up in the picture. In this case, for instance, objects such as the medication pill that should be taken daily at the same time and the universe of memories and reflections that it bring. One of the mothers said, “I have a complicated relationship with these medication tablets. I look at them and I remember the presence of the virus in my body that sometimes I wish to forget. But they are my guardians” (Magda, spring 2015). In the process of developing a ritual, as taking medication for example, the relation with time as a construct can differ from person to another. In other words, daily life events can be planned and measured against the time of taking the pill and it can be developed to remember special events that happen in the daily life through and by the time of taking a pill as a daily ritual.

HIV as a virus itself is somewhere in between an object and a subject. As a virus and living organism that mutates, gets activated or dormant it can give a sense of life within itself. One of the mothers said “ I call the virus Abbas. It is a name that

my friends in support group used to use to joke about the virus and hide for example while talking in public. For example, in a public place we can ask each other, how is Abbas doing today? Or is Abbas treating you well today? In a secret language that only us would know that we are talking about our HIV status and if we are tired today or not because of it” (Samira, spring 2015). Abbas is a name usually given to males and it is worth to note that it is kind of heavy name that is used in ironic way and in old Egyptian movies, we can find informants and males who have huge physique named as Abbas. For the *Kofta* device, Maha has certain facial expression while describing the device as if she is describing a monster creature which is much bigger than her. Her looks had the feelings of fear, wonder as well as helplessness.

Therefore, objects and talking about them like the device, the pills of the virus itself have carved their places in the new social relations developed as a result of living with HIV. Talking about the objects, imagining them together and relating to them in a secret language sometimes, indicates the affective relations developed along the living as an everyday process. This relation with objects are as dynamic as a relationship with a person in which new it can act as a probe to understand and reflect on one’s self.

Children, Family and the daily reconfiguration of maternal subjectivity

When I first met Maha, her sister accompanied her and she was tired from the consequences of her surgical operation. She said that she already sued the doctor as mentioned previously. While reflecting on her relations with her family, she said:

As a matter of fact, the suffering from the consequences of my surgical operation brought me back to my family. I saw my fathers’ tears of the first time. He was very compassionate and I thank God that this operations brought me back to my parents. I used to have conflicts with my family, especially with my father, and I preferred to live with my grandfather 8 years ago since I was diagnosed and before getting married. When I got married, I moved with my husband then to our flat and after I gave birth to our child in February 2011. My sister was always supportive to me. She takes care of my son along with her own son. The family of my husband, after he passed away, didn’t treat my child and me well. I have a small flat but it is far from where my parents live, so I stay with them these days most of the time for the sake of my child and my own health status. My child is being raised with many women taking care of him beside me. He is 4 years old now and he sometimes reminds me to take my medications. He doesn’t know of course medication for what, but he knows and see that his mother is sick. (Maha, Spring 2015)

Maha explained that her husband was taking care of their child all the time. He was eager to have a child and glad that their child was born and born healthy. After her husband's death, she suffered from depression and couldn't take care of her child well especially that she used to share the responsibilities of nurturing the child with her husband. After going through her surgical operations and the complications that happened because of the doctor, she was relieved to share the responsibility of raising her child in her parents' house with her parents and her sister's family. She expressed that her mother, her sister and her aunt are considered mothers to her child and they take very good care of him.

I get into depression and bad mood. It was a burden to feel so knowing that I have to take care of my child and making sure that he will not feel or see me in these sad and tired emotional and physical states. Now, he gets care from other people too and I don't feel that guilt burden when I suffer from bad days or unfortunate medical encounters. (Maha, Spring 2015)

Maha's statement on to be allowed to "get depressed" without feeling guilty about how the child perceives that brought to the surface one of the struggles of the mothering process. Being caught in between what she feels at the moment and what she is supposed to act like as a woman and as a mother in addition to the deep conviction that her child feels her. Hence, she felt obliged to work on her psychological well being, she does not want to give him negative feelings that he can not comprehend at his young age. She found relief in sharing her son upbringing with other women in her family and it was obvious in the way she articulated it. Her surgical operation and its complication brought up another collateral reality, as John law coins the term, which is getting back to her family, receiving help and sharing her motherhood responsibilities with them. Her ability to see and live this collateral reality while she is caught in the complications of unfortunate surgical operation and medical system that failed her was a clear indication of her agency and willing to live. Maha wishes that her son would be good at school and memorize the holy Quran, to guide him through life

Education is what will protect him in the future. I want him to memorize the words of God in the Quran and to be disciplined to be able to live well and for me to get assured on him. (Maha, Spring 2015)

Sama's son is with her most of the time. When we met, I gave him some white papers and pens to draw and he went to another room to draw and would come from time to time to show us his drawings. Sama takes her child everywhere with her and his father usually says that he is the "son of his mother" indicating that they are attached to a great deal.

We are kind of inseparable, but I don't see it as a load. He is like my little friend and he understands me and gives me unconditional love. He doesn't know what HIV is, but he comes with me when I go for routine testing or for support group. He is getting older and I think I will share with him my condition in the future, but not now. (Sama, Spring 2015)

As a matter of fact, Sama and her son looked more like friends in the way they were talking and arguing together when we were meeting. Their interaction was light and at ease. She considers him as her companion in life. She was also found it as a way to protect him. She didn't see her protection efforts as a load over her. "he takes care of me and I do take care of him, I see it as mutual thing for both of us" she said. She started talking about how she wants to see him when he grow up"

What I wish for my son the most is to be able to feel people. I don't wish for him to be a doctor or engineer as much as I wish that he would be sensitive and generous man. (Sama, Spring 2015)

My interlocutors' narratives here indicate how they organize and articulate their memories. Conceptually speaking, Dimitri Papadopoulos theorizes concepts of lived experience, agency and subject understood in relation to the process of "how memory works" (Stephenson & Papadopoulos, 2006). Papadopoulos argues that analysis of the techniques of remembering and how memory work provides a space to liberate the subject from a preconceived ideas of "linear and casual biographical narratives" (Stephenson & Papadopoulos, 2006). Hence, the subject emerges as a collective from multidimensional weaved structures that constitute her. He argues that memory-work as a process is presented in the articulated stories, which provide an opportunity to examine in the story "how we actively appropriate power relations, weaving ourselves into social structures that may or may not modify them" (Stephenson & Papadopoulos, 2006, p. 12). Moreover, Papadopoulos conceptualizes agency as it emerges within interpersonal social relations rather than the capacity to change or modify. In other words, agency is not static and linked to certain tangible outcome, rather as a dynamic process emerges in the act of sociability. Hence, as

Papadopoulos expressed, exclusion or inclusion in social relations is negotiated on daily basis through the act of sociability. (Stephenson & Papadopoulos, 2006).

What remains is what is unsaid

I've learned to value failed conversations, missed connections, confusions. What remains is what's unsaid, what's underneath. Understanding on another level of being. (A Nest of Quiet: A Notebook by Anna Kamińska)

Articulation as an act has a set of invisible dynamics and or politics that influence what is being told. When the spontaneous act of talking or articulating what is in the mind enter the zone of considering what should be told and what should not, here the politics of articulation are manifested. For instance, politics of articulation is a significant factor in social research and the outcomes of articulation process represented in the narratives can be constituted differently depending on who is conducting the research, the venue of research and methodology. This concept of articulation and its underlying politics were argued by Papadopoulos and Stephenson in their book 2006” *Analyzing everyday experience: Social Research and Political Change*”. Articulation itself is part and parcel of the social research efforts to examine experience, as they say,

The concept of articulation is a tool of the political project, and as such it has been immensely productive in shaping everyday life in post-colonial societies and amongst diasporas. However, we argue that much still remains unvoiced in the understanding of the relation between experience and the everyday entailed in articulation. What remains unvoiced is a whole world, World 2 as we call it, which resides inside the social space of liberal integration but deploys different forms of experience. (Stephenson & Papadopoulos, 2006, p. 15).

To articulate or to give a voice to describe certain reality might give a sense of clarity, courage, gathered equipped thoughts or transparency for the teller or the listener. However, how often we think about the conditions, surroundings or consequences in which these articulated narratives are produced? The world 2 as Papadopoulos points to remains in the unvoiced as well as the unseen and or unnoticed. More precisely, what inhabit world 2 is what was made unseen and unvoiced by different interlinked factors and considerations. I remember here an incidence I encountered in my previous professional community work and international work in the field of HIV and AIDS. I have witnessed incidences of selecting certain people living with HIV to speak on behalf of themselves and others

at national and international spheres. For instance, a man living with HIV was featured on a TV talk show in 2012, telling his story and the challenges of accessing treatment and the fears of rejection of treatment and care from health services providers. He was recognized among his neighbors and by the old management of the National AIDS Program. In a personal talk with him, he said that the old management of the National AIDS program threatened him because he did not take their permission to appear on the show and that would affect his treatment. Yes, people living with HIV attend different meetings and participate in different studies, however, the dominant structures of power and the context embracing their participation remains overlooked while producing information and statistics.

Concluding remarks:

In the stories narrated by the mothers, social recognition stemming within their everyday social relations, would manifest itself in its social and moral representation of motherhood. The mothers here didn't question motherhood in a direct way, it was like a given for them and they think of their children as a "blessing" and "compensation from God". Every time we talk about our children, there were smiles and appreciation in their eyes. I understand that they didn't have the privileged educational and analytical tools I got to study and read, but the reality is, they dealt with it in a more taken for granted and simple way. Motherhood was, for them, a way to be socially recognized and a success of some sort. They all decided to have children whether for the first time or after having elder children after knowing about their HIV status. Raising children has its burden and the mothers acknowledged that. However, they acknowledged it in the economic sense and the lack of proper health services for them and for their children. One of the mothers said "I wanted to have a healthy child who does not have HIV. I wanted to feel and prove that I can give birth and my child would be healthy"(Samira, Spring 2015).

All of them had some family members who knew about their HIV status whether from their family or from their in-laws family. To maintain certain representation as a woman who can get pregnant and give birth to, most importantly, a healthy child, was vital for the mothers' social relations as well as self-esteem. The moral representation of mothers in the Egyptian context would also contribute to reducing the stigmatized image of living with HIV, as one of the mothers said "I

know it would have been more difficult if I had HIV and not married, it would have been really cruel. My children, in some way, provide that social image that I need. Even between other women that I meet in our support group meetings” (Magda, Spring 2015).

Their lived experiences of raising their children give me an idea about different models of mothering. Yet, mothering is a process and an experience that is figured out daily and through their encounters with their children. Maha would share the process of mothering with others, while Sama is keen to have a friendship like relationship with her child. Sama also is keen to expose her child to her world. There are no concluding lessons on how mothering should look like; it lies in the lived experience of living with a child and how it constitutes the everyday with its dynamic, precarious nature. I find the questions that Papadopoulos asks in his book “Analyzing everyday experience: social research and Political Change, 2006”, (Stephenson & Papadopoulos, 2006) an important question, when he says, “Does the realm of the everyday structure our experience? Or is experience a tool which produces representations of the everyday?” (Stephenson & Papadopoulos, 2006, p. 12). Papadopoulos argued that experiences are not what constitutes the everyday and vice versa, lived experiences is what we should analyze and look for (Stephenson & Papadopoulos, 2006). In other words, subjects encounter many events in their everyday lives that might sound similar and gives some sort of conclusions on how to act or behave. However, it is not necessarily given that people will resort to those past experiences to comfort themselves or take conclusions for granted. They still encounter their own empirical reality every day. The rehabilitation of the precarious everyday livings is not concluded in an infinite possibility once knowing that some experiences happened before or to someone else.

Experience as a concept was described by Raymond Williams in his book *Keywords: A vocabulary of culture and society* (1985) as “the product of social conditions or of system of beliefs or fundamental systems of perceptions and thus it is not material for truths but as evidence of conditions or systems which by definition can’t explain itself” (Williams,1985, pp.128). Living with HIV leads to constructing a new social field shaped by the reaction of the persons themselves towards their own status and due to the actions of friends, family and colleagues (Lang,1991). However,

can experience be counted as an evidence describing certain social or personal reality? Joan Scott 1991 has dealt with that question in her article *The evidence of experience*. She argued that when the subject of enquiry is the main source of knowledge and at same time narrates her/his own experience, the core of the evidence of certain reality is granted and assured. She continues that other factors that drive the person to narrate their past and or present experience in certain structured way are secondary issue in that case and we get to see the different narratives of one issue told by many way which indicates the individualization and uniqueness of each case or as she stated it “the evidence of experience is then becomes the evidence for the fact of difference rather than a way of exploring how difference is established” (Scott,1991).

Acknowledging that in many stories, the decision to disclose if they are living with HIV with their families or not was out of their hands, however, they managed to regain this decision again while assembling their social again. While encountering the medical services that they routinely and crucially need, sometimes they don't share their HIV status with health practitioners. As much as it is important to feel safe and get tailored health services that respond to health needs of a person living with HIV, it is not always possible because of fear of stigma, refusal and mistreatment from health professionals (Khattab, 2010, p. 55). Having said that, a debate can be generated using the circulation of moral and epidemiological arguments that HIV positive people would harm the general public. However, I find those arguments generalized and lacking the dimensional analysis and awareness of understanding the context in which we are living in and neglecting the spider web of power dynamics and subordination. One of the mothers said:

I decide when to tell the doctor about my status when I think he is not taking care of the hygiene of his equipment or I simply leave the private clinic. I feel easier going to fever hospitals (*Homiyat Hospitals*) because this is where they treat people living with HIV especially if we needed to stay in the hospital, but I can't say that they treat us well there. It varies from a doctor to another and especially from nurse to another. My children are living in this country and they would need to go to doctors during the course of their lives, so I am aware that it starts with me not to contribute to circulating the virus in one way or another. I evaluate the situation, if it is medical examination that doesn't involve surgery, I don't share with the doctor. There is no need to. Yes, perhaps I think that he should know that I take HIV medication to write medication that doesn't contradict each other and affect my health. However, I

think again and feel that refusing to treat me or if he would mistreat me in any way is much dangerous for my health and my mood. (Magda, Spring 2015)

In this negotiation process with the self and with the healthcare provider, agency is obvious in the proactive way of the interacting and taking the lead to define her own world and everyday life. The consideration of the interlinked relations between the social and the medical manifested in the medical encounters and in the healthcare provider himself. Also, death due to HIV and AIDS is not considered as “good death” and this indicates that certain kind of causes of death have to be negotiated within the moral and social such as death from suicides for example or overdose of illegal drug or from HIV and AIDS. It all relates to the obvious moral economy of certain taboos such as sex, religion and drug use especially that the cause of death can reveal about the social living of the person.

Reflections

The ethnography situated the mothers' narratives, assembling the trajectories of the events that affected their lives to negotiate their present, into the political and social in Egypt. It is not only the person who has the virus in his or her blood who is affected and living with uncertainties. Main notions like uncertainty, fear, stress, solidarity, solitude, discrimination, helplessness, being judged and questioning the concept of "free-will" are expressed in our everydayness and mirrored in others.

It left me with more questions and endless curiosity and eagerness to continue navigating the consequences and updates of the events highlighted by them. This is a reflection rather than conclusion chapter as negotiating life is a continuous ritual which is practiced on a daily basis. Their agency, strength, warmth and future aspirations for their loved ones guided the path of this document. I started the fieldwork with a certain conceptual framework in mind. However, it changed during the fieldwork journey into the previously mentioned concepts in chapter one. I started the interviews with them without prepared questions or structured path. This way, I was absolutely ready to go with their own flow of thoughts, reflections and ordering of events. We listened to each other stories and their narratives re-ordered the branch questions of the main thesis quest and the final ordering of the chapters. All the events that they encountered, whether personal or coinciding with collective political reality in the country, are ongoing and didn't reach a certain end. Their present was not concluded by living with HIV and their everyday struggles and reflections are constituting the living, which resonates with Jacques Derrida's, when he said "It is originary: Life is survival" (Fassin, fall2010).

The concept of state is embodied in our everydayness, in the censorship of artistic works and movies, in the education system that intends to shape the identities of students whether based on nationalism or religion, in sanctioning certain groups and putting measures to limit their political participations or freedom of expressions or basically their mere existence! But how do people perceive these measures? Are they reducing the state to its governmental apparatuses only? Whenever, in the casual dialogue and nationalistic songs, we hear that the state is more important than the individual, aren't we getting absorbed in a bubble that we have created ourselves? These questions came to my mind while reading an article about the martyrs of the

revolution by Ahdaf Sweifvi and I imagine, three years ago, what were the masses thinking about when they were armed by their courage facing the heavy weapons and tear gas of the Ministry of Interior and the objection and discrimination of most of the people/nation describing them as thugs. The Egyptian flag along with Mina Daniel's red flag that was up for almost three consecutive days by Mohamed Mahmoud protesters made me question how do they perceive the nation and the state and how do I perceive it myself? What does it mean for them facing the main authoritarian forces in the country (Armed forces, Ministry of Interior and the Muslim Brotherhood)? Their endurance, courage and persistence would always give me hope that the hegemony forced by the concept of the sovereign state will be countered and dissected someday to understand its fluid nature and re-perceived hopefully by the young generations away from the way it was and is approached in education, media and public sphere.

Up till November 2015, the responsible people from the military who disseminated the false information about the HIV complete cure device didn't go under any trials. Meanwhile, the security and censorship grip over investigative media press and over freedom of expressions in general in Egypt is getting stronger. To the extent that journalists are being questioned for publishing investigative pieces in front of military prosecutors and called upon by military intelligence. On 8th of November 2015, Hossam Bahgat, an investigative journalist and Human Rights advocate was questioned by military prosecutions and "put under detention for four days, pending the investigation into charges of publishing false news that harms national interests and disseminating information that disturbs public peace"³⁰.

"Another nail in the coffin of the freedom of expressions in Egypt"³¹ Philip Luther said. Luther is the Director of the Middle East and North Africa Programme at Amnesty International. He also stated in Amnesty International's statement published on 8th of November 2015 "The Egyptian military cannot continue to consider itself above the law and immune from criticism". Sherif Mansour, the program Coordinator in Middle East and North Africa for the Community to Protect

³⁰ <http://www.madamasr.com/news/update-military-prosecution-orders-detention-hossam-bahgat-4-days>

³¹ <https://www.amnesty.org/en/latest/news/2015/11/egypt-arrest-of-prominent-activist-hossam-bahgat-another-blow-for-freedom-of-expression/>

Journalists commented "The Egyptian military has already indicated its contempt for the role of an independent media with a series of arrests of journalists. This latest detention is a clear attempt to stifle reporting .The Egyptian authorities should release Hossam Bahgat immediately. The fact that he was questioned for so long without his lawyers present only heightens the outrage."³² It is believed, through the different posts in social media, that Hossam Bahgat was prosecuted because he published an investigative piece investigating an article that was published earlier on BBC in August. However, the charges are not confirmed as stated by Heba Morayef, the current Associate Director for Egyptian Initiative for Personal Rights "Hossam Bahgat is being formally charged by the military prosecution. He still doesn't know what charges and has asked for lawyers"³³. Hossam Bahgat was released from military detention on 10th of November 2015 after pressure from multiple international and national entities, yet it was not clear if the charges against him were withdrawn or not.

Alia Abu Shuhba, in chapter two, was threatened to go under military prosecution if she published about the complete cure device during her work on her investigative piece on HIV medications³⁴. The efforts to control what is published and circulated between the people are ceaseless. The importance of investigative journalism to situate the information within certain context clearly documents an important phase of the history of Egypt. It is a crucial type of journalism which is faced with state scrutiny. The picture below, comprised from a photo and a statement, was circulated right after Hossam Bahga's prosecution on social media. The photo was taken to the Major General Ibrahim Abdilaty and the complete cure device with two medical doctors during the announcement of the device on 23rd of February 2014. The statement inside the picture reads" The Army is prosecuting the journalist Hossam Bahgat under military prosecution on charges of publishing false news and deluding the public discourse/ opinion. End of the Joke".

³² <http://www.madamasr.com/news/update-military-prosecution-orders-detention-hossam-bahgat-4-days>

³³ <http://time.com/4104248/egypt-hossam-bahgat/?xid=fbshare>

³⁴ Alia abu shuhba personal blog



Nov 8 at 9:42pm • Edited •

الجيش بيحاكم الصحفي #حسام_بهجت عسكرياً بتهمة تضليل
الرأي العام ونشر أخبار كاذبة .. خلصت النكتة.



Facebook, retrieved on 9th November 2015 1

The Complete cure device is often referred to it as the Kofta device as a matter of sarcasm and circulated in public discourse as a joke or example of deluding the people. The wittiness and resistance in Egyptian discourse to counteract political events and link the events to each other is evident in this example. It gives an idea that people understand, analyze and resist the authoritarian figures through sarcasm. And it gives the mere hope that events are not forgotten and will be “creatively” circulated till reaching a satisfying conclusion. I hardly found any story from the people who encountered the device published in any national media press. Additionally, the boundaries between social media outlets and audio-visual media outlets are elusive and they both influence each other and in continuous dialogue. What is being stirred on Facebook is discussed on national TV and radio channels and vice versa. All those modern communication technologies contribute to the discourse of resistance whether evident or sublime.

The incidence of the device brought the topic of HIV and AIDS into the public sphere. Journalists started writing investigative pieces and check what HIV represents and changed their language to be more oriented with the right to get treatment and explore the struggles of having chronic illness in Egypt. The influence that story cause and the courage to articulate it is tangible within some stories of people who are living with HIV in Egypt. In contrast to this, people with HCV didn't have this chance yet in Egypt. Many concealed stories are hidden in the fact that almost 20% of the

Egyptians have HCV and that it has a cure. Despite, the stories of encountering the HVC and the side effects of its medication are generalized and not unpacked.

An HIV positive person needs to monitor and manage her body to minimize immunity system relapses as much as she can. She had to do periodic blood tests and collects numbers to get informed and to understand what is happening inside her. A periodic checkup is advised for everyone; however, in case of HIV it is a matter of life or death. National institutions are publishing numbers to validate progress or deteriorations in their functions especially in critical times and different “produced” states of exception. And in between numbers, the living is happening.

The security grip and the moral panic around using “illegal” drugs, influenced my final decision to work with mothers who are living with HIV instead of people who are using illegal drugs on regular basis or as they are usually labeled as “drug addicts”. I started the research thinking of conducting the ethnography with people who use or inject drugs and not necessarily living with HIV. The goal was to examine how illegal substance use is being governed in Egypt and how the civil society works on harm reduction in regards to substance abuse. HIV governance would be one of the intersecting topics in this regard. However, the ethnography would have been challenging considering the criminalization of drug use and the security measures that find drug users guilty and arrest them. I got to know back then that prisons themselves have a lot of illegal drugs inside and if a drug user got jailed, there is a probability that he or she would come out of prison with shame and physical dependence on drugs, which is called addiction. Addiction with its moral politics combined with HIV was harder to examine than motherhood and HIV. The moral representation of mothering assisted in meeting my interlocutors and proceeds in the fieldwork because motherhood is a socially protected category after all.

While I was listening to the Judge’s final statement in Mubarak trial in December 2014 in which he emphasized the concept of morality and Egyptian morals as concluding remarks, I had the question of, how do we perceive morality? And what does it mean when authoritarian figures in the country emphasize it? Do we have the same understanding of such elastic and vague concept? Generally, people can’t argue with morality and virtues, or at the best would be obliged to think in binaries and take

sides, when it is used in a conversation or they will be perceived as immoral. The same goes with religion or science, which lend them their authoritative grip. I find it oppressing in a way or another when such vaguely perceived constructs, such as morality, are adopted as a governing tool that silence who doubts or jails who questions the why and how of many social, personal and political as well as economic issues. Meanwhile, States of distractions are created through different media outlets with authorities' blessings, doing their work in distracting the public through creating moral panics and propagating them. Terrorized mutually constitutive public and private spaces are emerged in such living states of visible scrutiny.

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i Global AIDS Response Progress Reporting Guidelines for 2012

ii <http://www.wac-eg.info/hiv-in-egypt/>

iii Egypt Demographic and Health Survey 2008

iv The workshop was conducted with Youth Association for Population and Development (YAPD). I was responsible for providing the technical content and interactive workshops on HIV and AIDS in 5 governorates (Cairo, Alexandria, Aswan, Luxor, Minya)

v Deleuze, G. 1992. Postscript on the Societies of Control

vi <http://www.shorouknews.com/columns/view.aspx...>

Note:

The name Cantus Lamentus was inspired by the music piece that has the same name composed by Dhafer Youssef <https://www.youtube.com/watch?v=XA805hs8CT0>

Cantus is the Latin word for singing, especially singing in an ensemble. I was inspired by the stories of the mothers I met while doing my fieldwork for this thesis. Their personal narratives with all its differences and resemblance, lamented and cheerful moments sounded to my mind as if they are a choir chanting together. Their composed narratives are weaved together to transcend their own stories providing a background of melancholic melodies for the everyday events of the precarious living; with all its random, chaotic yet lively and pulsating encounters. Those stories implied their continuous act of mediating the political, the social and the medical circumstances that they are living within while living with HIV. The stories carried vibes of sorrow and melancholy, as they are figuring out, on daily basis, how to survive the demands of their roles as mothers, workers, women and Egyptians. However, while they are articulating what they perceived as transforming and memorable events in their lives, streams of faith were tangible in their continuous act of negotiating the consequences of appalling life events. As if they were singing their sorrows out bringing to the picture the cathartic power of the act of singing itself. However, it also indicates that their song can be passed by or overlooked as the case with many songs and stories we encounter. Their choir is singing a song, melancholic yet beautifully

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sensible, and it is about their lives in Egypt. It gives room to contemplate, relate to and reflect on the art of living itself. That is what music does to the listener, and that is what happened to me while encountering the stories that they, thankfully, shared with me.